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Occupational Therapy Practice In Assessment Of Older Person's Decision Making Capacity To Return Home-An Exploratory Study

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OCCUPATIONAL THERAPY PRACTICE IN ASSESSMENT OF OLDER PERSON'S DECISION MAKING CAPACITY TO RETURN HOME-AN EXPLORATORY STUDY

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A dissertation submitted in partial fulfillment of the requirements for the degree of MSc in Neurology & Gerontology.

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DECLARATION

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a Master of Science Neurology & Gerontology is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

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SUMMARY

Introduction

Decision Making Capacity (DMC) refers to an individual's ability to make a reasoned and informed decision. In Ireland the older population is increasing and associated with ageing are functional and cognitive decline which are linked to reduced decision making abilities. In an acute hospital an individual's DMC is often questioned and a DMC assessment takes place. Occupational therapists are involved in this process and evaluate an individual's cognitive and functional abilities. This study sought to explore the practices of occupational therapists in this process.

Aims and Objectives

Aim: To explore occupational therapists assessment practices in DMC of the older person to live independently.

Objectives: To examine occupational therapists understanding of DMC, assessments used in process and to explore the outcomes of assessment findings.

Methods

The study employed a qualitative description design using semi-structured interviews with ten hospital occupational therapists from seven hospitals. Key themes emerged from analysing the data using thematic analysis.

Results

Three themes emerged from the data; Pre-assessment, Assessment and Post Assessment. Pre-assessment, participants formed their understanding of DMC and sought to build a detailed picture of the individual prior to their hospital admission. The assessment phase consisted of standardised and non-standardised assessments. Standardised assessments were used to evaluate cognitive performance while non-standardised assessments evaluated an individual's Instrument Activities of Daily Living (IADL's). Assessments focussed on IADL performance and if possible were completed in the home environment. Post Assessment all results were documented in the medical chart and verbally to the multidisciplinary team and focussed on the level of assistance an individual would require for independent living.

Conclusion

Observational assessments of IADL's in particular in the individual's home were considered the most pertinent part of the occupational therapy assessment.

Implications

Occupational therapists require practice guidelines and further training to support their involvement in this process.

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LIST OF ABBREVIATIONS

ACE III: Addenbrooke's Cognitive Examination III

ADL: Activity of Daily Living

AOTI: Association of Occupational Therapists in Ireland

CASP: Critical Appraisal Skills Programme

DMC: Decision Making Capacity

IADL: Instrumental Activity of Daily Living

ILS: Independent Living Skills

MDT: Multidisciplinary Team

MMSE: Mini Mental State Examination

MOCA: Montreal Cognitive Assessment

OT: Occupational Therapy/ Occupational Therapist

P: Participant

PIL: Participant Information Leaflet

QD: Qualitative Description

RCAT: Regional Capacity Assessment Team

RCSI: Royal College of Surgeons in Ireland

RUDAS: Rowland University Dementia Assessment Scale

UK: United Kingdom

US: United States

INTRODUCTION

Decision Making Capacity (DMC) refers to an individual's ability to make a reasoned and informed decision (Moberg and Rick 2008). It is composed of four components; the ability to understand the necessary information, to appreciate the relevance to one's own situation, to weigh up the consequences of the decision and to communicate a choice (Moye et al 2006). All adults are presumed to possess decision making capacity but should concerns exist regarding an individual's decision making ability, a DMC assessment is completed (Suleman and Hopper 2015). The assessment aims to establish if the individual has the necessary cognitive abilities to make the specific decision and thus protect those who are unable to make informed decisions from serious harm (Tunzi, 2001). There are at least eight categories of decision making capacity; independent living, financial management, driving, consent to treatment, sexual consent, research consent, voting and testamentary consent (Moye and Marson 2007). As each category requires different skills a separate assessment is required for every decision (Ganzini et al 2003) with independent living being the most frequently assessed (Hazelton et al 2003).

In Ireland the older population is steadily increasing and it is estimated that by 2041, 22% of the population will be over 65 years old (O'Regan et al 2011). Associated with increasing age are physical and cognitive decline, both of which are linked to reduced decision making ability (Moye and Marson 2007). In an acute hospital the issue of decision making capacity for independent living frequently arises when staff and family raise concerns regarding an individual's ability to manage at home (Emmet et al 2013; Christensen et al 1995). A DMC assessment is completed by a medical Consultant and seeks to determine if the individual has a realistic understanding of their abilities in order to make a decision about the amount of assistance necessary for independent living (Hazelton et al 2003; Moye et al 2006). Occupational therapists can make important contributions to decisions on an individual's ability to return home (Darzins, 2010). Occupational therapists assess an individual's physical and cognitive abilities while considering the impact of the social, cultural and physical environment. The assessment includes the use of skilled observation and standardised assessments to

determine an individual's performance with everyday activities (Reed and Sanderson 1999). Occupational therapists can then make recommendations on the level of support an individual may require for independent living (Darzins, 2010).

Despite their involvement in DMC assessments, there is a dearth of literature that examines how medical professional's view decision making capacity and their approach to the process (Moye and Marson 2007). In December 2015 the Assisted Decision Making (Capacity) Act 2015 was enacted. The Act describes the components of decision making capacity but does not outline the role of health professional involved in the process (Assisted Decision Making (Capacity) Act, 2015). Considering the rising older demographic in Ireland and the recently published legislation, research on health professional's involvement in DMC assessments is very relevant. The aim of this study is to explore the practices of hospital occupational therapists in the assessment of older person's capacity to live independently. It is hoped this study will enable a greater understanding on the topic and may assist in the development of practice guidelines for occupational therapists in decision making capacity for independent living. The study will present a critical review of the literature in relation to the topic in chapter one.

CHAPTER 1
LITERATURE REVIEW

1.1 Introduction

The aim of this chapter is to give an overview of the current evidence regarding Decision Making Capacity (DMC) in older adults, factors that influence decision making capacity, the decision making capacity assessment process and the potential role of occupational therapy. The information was derived from searching several electronic databases using varying search terms. The critical appraisal tool used to review the literature was the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (http://www.casp-uk.net).

1.2 Decision Making Capacity

Decision making capacity is the ability to make informed and reasoned decisions relating to financial, self-care, residential, medical and legal issues (Moye et al 2007). It is presumed that every individual possesses decision making capacity (Venesy, 1994) and in most countries, an individual is legally able to make their own decisions from 18 years of age (Mullaly et al 2007). Decision making capacity is regarded as a mental capacity (Dekkers, 2001) composed of four decision making components; the ability to understand the necessary information, to appreciate the relevance to one's own situation, to weigh up the possible consequences of the decision and to communicate one's choice (Etchells et al 1999; Moberg and Rick 2008; Karlawish, 2008). Decisional incapacity occurs due to a lack of one or more of these four components (Capozzi and Rhodes 2002; Emmett et al 2013).

Decision making capacity is not a global, encompassing concept (Newberry and Pachet 2008) as each decision requires a different level of complexity. As such, an individual may possess the capacity to make one decision and not another, necessitating the need for a separate assessment for every decision (Ganzini et al 2003). Decision making capacity may change over time and incapacity may be temporary (Lo, 1990) and caused by a transient medical or mental health condition such as delirium or depression

(Mullaly et al 2007; Woods and Pratt 2005). Decision making capacity is likely to decrease with advancing age (Fitten and Waite 1990) when weakness and frailty or the presence of a cognitive impairment may cause concern into an individual's decision making processes (Venesy, 1994; Moye et al 2004). A decision making capacity assessment may subsequently be required to determine an individual's decision making abilities (Suleman and Hopper 2015).

1.3 Decision Making Capacity of Older Adults

In Ireland our population is ageing at an increasing rate and it is predicted by 2041, 22.4% of the population will be over 65 years of age. Of those over 80 years of age, one third will present with some form of cognitive impairment (O Regan et al 2011). Adults over 65 years of age are three and a half times more likely to experience a hospital admission than those less than 65 years (Fitten and Waite 1990). During a hospital admission older adults are at significant risk of functional and cognitive decline (Wales et al 2012) which are intrinsically linked to reduced decision making abilities (Moye and Marson 2007). The areas of decision making capacity that most commonly pertain to the older population are; testamentary consent, financial management, driving, consent to treatment, sexual consent, research consent, voting capacity and independent living (Moye and Marson 2007). Most research to date has focussed on the domains of financial and consent to treat categories (Mullaly et al 2007) however this review will focus on the area of independent living.

1.4 Assessment of Decision Making Capacity

In the past decision making capacity was determined solely on a diagnosis which was referred to as the status approach. An individual was deemed incapable of making decisions on the basis of a psychiatric or neurological illness (Moye et al 2004). This approach assumed all decisions were of equal complexity (Wong et al 1999) and that the presence of a physical or mental disability inferred an inability to make decisions (Silberfeld and Checkland 1999). It is widely accepted that both of these assumptions are untrue and the status approach is now considered inappropriate (Skinner et al 2011; Wong et al 1999). The status approach failed to consider the heterogeneity of a population by assuming all individuals from a particular group for example individuals

with dementia were incapable of making decisions. This is not in keeping with human right principles (Emmett et al 2013) and has since been replaced with the functional approach (Silberfeld and Checkland 1999).

The functional approach involves determining if the individual possesses the four components necessary for decision making (Karlawish, 2008). These components are the ability to understand the information relating to a decision, relate the information to one's own situation, appreciate the consequences of deciding one way or another and communicate a choice (Stewart et al 2005). Most countries have now adopted the functional approach and incorporated it into legislation for example it is underpinned in the Mental Capacity Act 2007 in the United Kingdom. Subsequently, medical professionals employ this method of assessment which focuses on the individual's relevant abilities and the extent to which these abilities match the demands of the particular decision (Wong et al 2000). In Ireland, the Assisted Decision Making (Capacity) Act 2015 also describes a functional approach to decision making capacity assessments (Assisted Decision Making (Capacity) Act 2015).

A decision making capacity assessment is currently completed by a medical Consultant (Tunzi, 2001) and the process usually involves a medical review, an interview and assessment of the individual's cognitive abilities (Fitten and Waite 1990). The interview may be unstructured or semi structured and aims to explore the individual's ability within the four components of decision making capacity (Etchells et al 1999; Pachet et al 2010). The decision making capacity assessment is focussed on how the individual reaches their decision and not on the decision itself (Ganzini et al 2003). As such, assessors are ethically obliged to allow individuals to make decisions which they may not agree with (Macciocchi and Stringer 2001; Sexton, 2012). The assessment methods used to determine decision making capacity have received repeated denunciation (Breden and Vollmann 2004). It is argued that unstructured interviews are subjective and inconsistent (Volicer and Ganzini 2003) and that medical professionals may overly rely on informal clinical impressions (Etchells et al 1997). The semi-structured interview tools are reported to lack specificity, over-diagnose incapacity and fail to consider contextual factors such as the assessment environment (Brenden and Vollmann

2004; Okai et al 2007). Finally it has been demonstrated that there is considerable variances in the agreement between the unstructured and semi structured methods for determining decision making capacity (Moye and Marson 2007; Moye et al 2006).

1.5 The Impact of Cognitive Ability on Decision Making

Cognitive ability is considered an important factor in decision making capacity assessments (Sessums et al 2011; Moye et al 2007). Cognitive ability and decision making capacity are correlated but are not the same entity (Lo, 1990). Cognitive ability incorporates a wide range of processes such as memory, attention and problem solving (Ganzini et al 2003). While some of these cognitive abilities are necessary for decision making, cognitive ability refers to a wider range of processes (Ganzini et al 2003). It appears there is an over-reliance on cognitive tests, which indicate the presence or absence of a cognitive impairment in decision making capacity assessments (Lo, 1990). The literature frequently refers to overuse of the Mini-Mental State Exam (MMSE) (Etchells et al 1997) but there are many other cognitive tests. These tests include the Montreal Cognitive Assessment (MOCA) (Cohn, 2014) and the Rowland University Dementia Assessment Scale (RUDAS) (Limpawattana et al 2012) but these do not appear to be discussed in the literature on decision making capacity.

Most authors agree the MMSE is an inadequate measure of decision making capacity (Allen et al 2003; Kim et al 2002). The MMSE and many other cognitive tests do not sufficiently assess comprehension, reasoning or judgement (Sachs and Kirschner 2000). Caution should be erred as poor performance may be attributed to other factors such as low levels of education (Buam and Edwards 1993; Cattarinich et al 2001). Cognitive tests do not adequately capture the everyday functioning of older adults and do not consider the merits that experience and familiarity offer to the older person in performance of their everyday tasks (Allaire and Marsiske 2002). This has led to the questioning of the external and ecological validity of cognitive tests (Diehl et al 1995; Mullaly et al 2007). It has been suggested the focus should change from cognition as it is traditionally assessed to applied cognition. This is the use of cognitive abilities to carry out activities of daily living (ADL's) (Willis, 1996). Contextually relevant assessments measuring the older person's ability in their natural environment may be

more appropriate and information rich (Allaire and Marsiske 2002). As such cognitive tests may be best combined with measures of ADL performance (Breden and Vollmann 2004). In America, many states require an evaluation of an individual's everyday living skills for decision making capacity assessments for independent living (Moberg and Rick 2008). The recommendation for a functional evaluation is made under the Uniform Guardianship and Protective Proceedings Act 1997 and while it is a requirement in 16 states the Act does not describe what the functional evaluation should entail (Moye et al 2007).

It is acknowledged that individuals with a mild cognitive impairment may experience a decline in their ability to carry out ADL's (Okonkwo et al 2008). Initially, the changes in functional ability are observed in Instrumental Activities of Daily Living (IADL'S). IADL's refer to the more complicated everyday tasks such as driving, medication management, money management, housekeeping and meal preparation (Fricke and Unsworth 2001). There is increasing evidence that performance on basic ADL's; washing, dressing and feeding may remain intact as it is proposed that there is minimal reliance on cognitive processes for these tasks (Allaire et al 2009; Carswell and Eastwood 1993). Therefore, assessments that are performance based may need to focus on IADL's as there is an over-reliance on self-care activities which have a performance ceiling effect (Diehl et al 1995; Carswell and Eastwood 1993).

1.6 Decision Making Capacity in the Acute Hospital

Evaluating an individual's decision making capacity is a daily occurrence in an acute hospital (Carroll, 2010). Figures for the United States estimate this affects one third to a half of all hospital inpatients (Seyfried et al 2013). The question of decision making capacity frequently arises when an inpatient wishes to return home after discharge but health professionals express concerns regarding their safety (Stewart et al 2005). Relatives may also relay fears that home is no longer the safest option and contrary to the patient's wishes, propose that a long term care facility is required (Emmett et al 2013). These patients are more likely to be of advanced age, have physical limitations, a moderate cognitive impairment, varying levels of communication and often show limited insight into their level of dependency (Brindle and Holmes 2004). Placing an

older individual into a long term care facility against their wishes is an infringement of basic human rights. However, allowing that individual to return home with impaired memory and judgement and a poor acknowledgment of risk may be negligent (Stewart et al 2005). This highlights the complex nature involved in determining an individual's decision making capacity for independent living which is a fine balance between beneficence and autonomy (Wong et al 1999).

1.7 Factors that Influence Decision Making Ability in Older Adults

The older population is a diverse group and as such there are multitudinous factors that impact on their decision making. Some of these influencing factors include personality, education, experience, social and emotional function, culture, race, religion and cognitive ability (Rabin et al 2008; Christensen et al 1995; Moye et al 2006). Generational differences are also a significant consideration as older persons may assume that family or health professionals will make the decision and take a less prominent role in the decision (Moye et al 2006). The process of being hospitalised can affect an individual's decision making ability as infection, dehydration, depression, medication interactions and delirium may all cause decisional ability to fluctuate (Fitten and Waite 1990). As an acute hospital can be a disorientating place for individuals with cognitive impairments it can be a challenging environment in which to make important decisions (Venesy, 1994; Sexton, 2012). Often decision making capacity is established too early in a patient's hospital stay due to pressures on hospital beds without sufficient consideration of all influencing factors (Hazelton et al 2003; Stewart et al 2005).

1.8 The Role of the Multidisciplinary Team in Determining Decision Making Capacity

The presence or absence of decision making capacity should ideally be determined by a multidisciplinary team of professionals (Suleman and Hopper 2015). Many international facilities have set up multi-disciplinary panels to ensure that decision making capacity assessments are based on objective criteria (Hazelton et al 2003). In Canada, the Regional Capacity Assessment Team (RCAT) was established in 2005 to assess decision-making capacity and address capacity issues within the Canadian area of

Calgary. This multidisciplinary team, which was the only one of its kind in Canada at the time, was set up to address the inconsistencies frequently observed in the decision making capacity process. RCAT acknowledges that capacity determination assessments require an appropriate mix of knowledge and skill in order to protect the vulnerable. The team members consist of a physician, social worker, psychologist and an occupational therapist and accept referrals for individuals with dementia, brain injury, psychiatric illness, addiction and intellectual disability. A psychosocial assessment is completed which includes social and family history, religious and cultural factors. An environmental assessment is conducted by an occupational therapist and evaluates the individual's functional abilities in their own home. RCAT places limited emphasis on cognitive abilities and a greater focus on the individual's social functioning and capabilities (Newberry and Pachet 2008). The inception of multidisciplinary teams such as RCAT appears to support the need for a functional evaluation of the individual particularly in their own environment and thus highlights the contribution of occupational therapy.

With regard to speech and language therapy, Ferguson et al (2010) explored nine therapists' views on decision making capacity for patients with aphasia. This Australian qualitative study conducted nine telephone interviews. The results reported that all therapists used informal observation in their assessment process. This involved observing functional communication skills on the ward, in the home environment and in the community. All participants stressed that this method of assessment was the most relevant approach to inform clinical decisions. Therapists also administered standardised assessments although there was no agreement on which standardised assessments were most appropriate. All therapists highlighted a need for the development of practice guidelines for speech and language therapists in decision making capacity assessments. The authors hypothesised that due to the lack of resources and training it appeared that speech and language therapists working in this area had developed the necessary skills and competencies through experience and peer support with little formal training.

Aldous et al (2014) completed an online survey on decision making capacity with 51 speech and language therapists working in neurological practice. This study focussed only on patients with communication difficulties and not on those with a combination of cognitive and communication deficits. The authors reported that therapists employed both standardised and non-standardised assessments with similar frequency. The heterogeneity of assessments approaches identified; standardised, non-standardised, semi-structured; liaison with family and multidisciplinary team members demonstrated that one uniform method of assessment was not appropriate. The individualised assessment approach also incorporated structured discussion with multidisciplinary team members which was considered valuable in therapist's clinical reasoning. Again, the need for practice guidelines in this area was identified by all therapists.

Suleman and Hopper (2015) explored the perspectives of 15 speech and language therapists on decision making capacity assessments for patients with aphasia in Canada using semi-structured interviews. The study reported that therapists considered decision making capacity assessments as language based with little consideration for individuals with communication deficits. All therapists recommended that the assessment process and materials should be modified to facilitate individuals with language difficulties. Participants identified potential roles for speech and language therapists in these assessments as an assessor, educator and advocate. The limitations in generalising the findings from these three studies are that they pertained to speech and language therapists only and to all categories of decision making capacity; not solely to capacity to live independently. Furthermore, there may be a limitation in applying international literature into an Irish context due to the differences in health care service structure and provision.

1.9 The Role of Occupational Therapy

Functional assessments are a fundamental skill of occupational therapists who evaluate ADL and IADL performance through observation (Robertson and Blaga 2013; Brown and Finlayson 2014). Occupational therapy examines the physical, psychological and social functions of an individual while considering the social, cultural and physical environment (Radomski and Trombly 2008). The focus that occupational therapy places

on functional assessments supports their role in decision making capacity assessments for independent living. Occupational therapists appreciate that cognitive ability impacts on function and use standardised cognitive tests as part of their assessment (Robertson and Blaga 2013). These cognitive tests include the MOCA, Independent Living Skills (ILS), RUDAS and the Addenbrooke's Cognitive Examination III (ACE III) (Cohn, 2014; Limpawattana et al 2012; Jubb and Evans 2015).

In decision making capacity assessments for independent living, Newberry and Pachet (2008) stressed the importance of reviewing the individual in their own environmental context to consider the supports and limitations it offers. Home visits are frequently completed in occupational therapy practice which involves evaluating an individual's functional performance in their own environment (Atwal et al 2014). These visits provide valuable information on physical, social and environmental limitations and assist occupational therapists in making recommendations on the level of assistance an individual will require at home (Robertson and Blaga 2013). Considering the cognitive and functional areas of evaluation in decision making capacity assessments there appears to be a role for occupational therapy in this process.

1.10 Summary of Review

This literature review clearly highlights a potential role for occupational therapy in the process of decision making capacity for independent living. Considering the rise in the ageing population in Ireland, it is likely the rate of decision making capacity assessments will increase. However, based on the literature search for this review there appears to be limited information on the role of occupational therapy in the process. This qualitative study aims to explore the practices of hospital occupational therapists in determining older person's capacity to live independently. It is hoped to gain insight into occupational therapists understanding of decision making capacity and their assessment approaches. It is anticipated that this could potentially lead to larger scale studies with a view to supporting the need for practice guidelines for occupational therapists in the decision making capacity process. The methods used to initiate, conduct and analyse the study will be discussed in the next chapter.

CHAPTER 2
METHODOLOGY

2.1 Aims

This study aims to explore the assessment practices of hospital occupational therapists in decision making capacity of the older person to live independently.

2.2 Objectives

- To determine occupational therapists understanding of decision making capacity for independent living
- To ascertain the assessments completed by occupational therapists in decision making capacity for independent living.
- To explore the outcomes of assessment findings.

2.3 Research Design

The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used throughout the design and analysis of this study (Tong et al 2007). Qualitative research has much to offer those studying health services (Pope and Mays 2013) and furnishes occupational therapy with a valued source of evidence (Curtin and Fossey 2007). The research methodology guiding this study was Qualitative Description (QD) as described by Sandelowski (2000). Qualitative description is used to describe people's perceptions and experiences of a phenomenon and aims to provide a comprehensive summary of events in easily understood language (Sandelowski, 2010). Qualitative description does not aim to provide theory development or interpretive meaning of events or experience (Sullivan-Bolyai et al 2005) and has no alignment to a philosophical or theoretical position (Stanley and Nayir 2014). Qualitative description is a useful method for many research questions in health care because it can help to focus on the experiences of patients, relatives and professionals (Neegaard et al 2009). This assists in providing clear information on ways to improve care provision (Sullivan-

Bolyai et al 2005) and was considered a suitable methodology for this study exploring occupational therapists' practices in determining older person's capacity to live independently.

2.4 Participants

The study used purposeful sampling which entails deliberate, non-random sampling of a group of people with a particular characteristic (Carter and Henderson 2005). The participants were acute hospital occupational therapists with experience of decision making capacity assessments of older adults for independent living. In qualitative description, gaining and illustrating a truly insider perspective of the research topic enhances the authenticity of study findings (Neergard et al 2009). Thus it was anticipated that due to the greater bed capacity in acute hospitals the process of decision making capacity for independent living would occur more frequently. Data saturation is achieved when data informs existing findings but does not offer anything new and often guides qualitative sample size. However, data saturation is particularly difficult to achieve in qualitative description because the aim of analysis is to capture individual participant meaning and to explore commonalities and differences (Milne and Oberle 2005). It is important to note that in qualitative studies, a smaller sample size may be used as this type of research does not require a representative sample (Stanley and Nayar 2014). A small sample size is advised when the scope of the study is more focussed (Morse, 2000; Hansen, 2006) and this study explored only acute hospital occupational therapists practices and focussed on one category of decision making capacity; independent living. As such ten occupational therapists were selected for this study.

2.5 Inclusion and Exclusion Criteria

The inclusion criterion was any acute hospital occupational therapist working in Ireland with at least one year's clinical experience. It was hypothesised that any therapist working less than one year may have insufficient experience of decision making capacity for independent living. As such the exclusion criterion was any occupational therapist with less than one year's clinical experience.

2.6 Recruitment

The participants were sourced through the Association of Occupational Therapists in Ireland (AOTI). AOTI acted as a gatekeeper and emailed a description of the study and the lead researcher's details to all of its members. Two weeks after the initial email a reminder email was sent to all members. Those who wished to take part in the study contacted the lead researcher and the first ten respondents that met the inclusion and exclusion criteria were selected. As the sample size was ten, once ten participants were recruited subsequent respondents were advised that the recruitment process had ceased.

2.7 Data Collection Methods

Semi-structured interviews with-open ended questions were used to facilitate an in-depth understanding into the practices of hospital occupational therapists in decision making capacity of older adults to live independently (Britten, 1995). In qualitative description, semi-structured interviews are used to elicit specific data in relation to the research aims (Milne and Oberle 2005). Semi-structured interviews are frequently used by health care professionals in research (DiCicco-Bloom and Crabtree 2006) as all participants are asked the same questions within a flexible framework (Neegaard et al 2009). The advantages of interviews are that issues can be clarified and probed further as necessary (Bowling, 2014). The disadvantages are that the data are time consuming to collect and analyse and there is greater potential for interviewer bias to take place. Interviews were selected in favour of focus groups as interviews allow a more relaxed research atmosphere in which to gain sensitive information (Bowling, 2014). An interview schedule (Appendix 1) of questions and prompts is a useful means of focussing on the pertinent data (Lewis and Ritchie 2003). This was devised in accordance with the aims and objectives of the study, in collaboration with both study supervisors and with consideration of the literature. The interview guide began with participants' characteristics; years of experience, staff/senior grade post and current client profile which allows the reader to consider the relevance of the findings to their own situation (Tong et al 2007). The interview was divided into three domains in accordance with the study objectives and within each area, there were several prompts to ensure adequate exploration of each topic. In qualitative description, the interview guide is slightly more structured than in other qualitative methods and is typically

focussed on areas that are poorly understood in a health care context (Neegard et al 2009).

2.8 Pilot Interviews

The interview schedule should be reviewed to ensure it enables participants to give a full and coherent account of their experiences (Lewis and Ritchie 2003). For this reason, two pilot interviews on current work colleagues in Our Lady of Lourdes Hospital, Drogheda were completed to allow for further refinement of the interview schedule. Following this, an additional question was added to the interview schedule; 'what was the prompt/trigger that caused an assessment of the individual's decision making capacity?'. The pilot interviews were transcribed and analysed as a means of gaining experience in thematic analysis but the data were not used in the study results.

2.9 Data Collection

All interviews took place at a location of the participant's choice and ranged from 26-62 minutes in duration. As recommended by Coombes et al (2009) the interviews were recorded using a diactaphone to ensure all salient pieces of information were captured. The interviews were transcribed verbatim by the lead researcher within two days of recording as this assisted with transparency of data collection and interpretation (Bryman, 2012). Each participant was sent a copy of their transcript for member checking which provided the participants with an opportunity to review the data and ensure it was an accurate reflection of their opinions (Creswell and Miller 2010).

2.10 Data Analysis

The six stages of thematic analysis as described by Braun and Clarke (2006) was completed by the lead researcher (Fereday and Muir-Cochrane 2008). Stage one involved becoming familiar with the data; the lead researcher conducted and transcribed the interviews which helped to develop an understanding of the data. Stage two generated initial codes which involved labelling portions of the data in order to organise the data into meaningful groups. A qualitative data analysis computer programme, QRS International's NVivo 8, was used by the lead researcher to assist with organising and

coding the interview data (Krippendorff, 2004). NVivo 8 assisted with searching, marking, up-linking and organising the data which allowed the lead researcher to analyse the data in a more time efficient manner and to revise the analysis (Denzin and Lincoln 2000). The software also allows the researcher to record all interviews and demographics in one location (Denzin and Lincoln 2000) and enables the production of an audit trail as the software completes logging of data movements and coding patterns (Thomas and Magilvy 2011). Stage three ensured that all of the data were coded and then the codes were developed into themes. Stage four refined the themes; the lead researcher reviewed the coded data by reading the data set for each theme and ensured that the data set accurately reflected each theme. The themes were defined and named in stage five and the lead researcher identified the meaning of each theme in relation to the research aims and objectives. For the sixth and final phase of analysis; producing the report the lead researcher completed a concise and logical account of the identified themes. To optimise rigour an external validator completed stages one to three of data analysis with three transcripts. The external validator was not directly involved in the study but was asked to analyse three transcripts. The external validator practices as an occupational therapist and has previous experience with qualitative research. This process is referred to as triangulation analysis, which is a process where the same problem is investigated from different perspectives to enhance validity (Yardley, 2000) and is a powerful method for enhancing credibility (Krefting, 1991). A meeting took place between the lead researcher and the external validator where all codes and themes were compared, discussed and reviewed. To ascertain the rate of inter-coder agreement; the number of agreements was divided by the total number of agreements and disagreements. The recommended inter-coder agreement is 80-95%. As initial agreement was 70%, the process was repeated and agreement reached 85% (Miles and Huberman 1994).

2.11 Ethical Considerations

An application for ethical approval was submitted to Royal College of Surgeons in Ireland's (RCSI) Research Ethics Committee (Appendix 2) on August 25th 2015. Ethical approval was granted on October 15th 2015 (Appendix 3). The study details and the ethical approval letter were submitted to the Association of Occupational Therapists in Ireland (AOTI) on October 15th 2015 and an email was sent to all AOTI members on

November 4th 2015. Any interested members who wished to take part contacted the lead researcher by telephone or email. If the potential participant met the inclusion and exclusion criteria a copy of the participant information leaflet (Appendix 4) and consent form (Appendix 5) was sent by post or email. The participant information leaflet explained the rationale for the study and contained the contact details of the lead researcher, supervisor and co-supervisor should anyone have any further questions. The consent form was signed by all participants prior to conducting the interviews which took place from November to January 2016. Once all interviews were transcribed the dictaphone recordings were deleted and no therapist or hospital was named in the transcripts. All transcripts were coded (e.g.) P1, P2 with one master document that detailed which codes related to which participant's details should any participant later wish to withdraw their information from the study. All transcripts, signed consent forms and any study documentation was scanned, encrypted and stored in a password protected file on the RCSI V drive. All information will be stored for five years accordance with RCSI policy and no information was saved on personal laptops. A secondary analysis of the data was completed by an external validator who had access to three transcripts but not the audio recordings. To facilitate this analysis, the external validator was supplied with an encrypted USB device from the lead researcher which was returned once thematic analysis was completed.

2.12 Methodological Strengths and Limitations

2.121 Trustworthiness

Qualitative research is often criticised for lacking rigour or trustworthiness (Anderson, 2010) which is the extent to which the findings are an authentic reflection of the phenomenon being studied (Curtin and Fossey 2007). Four criteria for trustworthiness in qualitative studies that are widely accepted were proposed by Lincoln and Guba; credibility, dependability, confirmability and transferability (Shenton, 2004).

2.122 Credibility

The study is considered credible if the reader considers the findings represent some element of truth (Thomas and Magilvy 2011). To enhance the credibility of the study,

the transcripts were audio recorded and transcribed verbatim to ensure verification of the participant dialogue (Shenton, 2004). All participants were offered a copy of their transcripts for member checking to provide an opportunity to ensure that the information was true and accurate (Curtin and Fossey 2007). The lead researcher analysed each transcript on two separate occasions and compared the analysis to ensure agreement of the codes and themes. To further ensure credibility, three transcripts were coded independently of the lead researcher by an external validator who was a previous occupational therapy work colleague with post graduate experience in qualitative research. A meeting took place to compare codes and any disagreements were discussed until a consensus was reached (Liamputtong, 2009).

2.123 Dependability

Dependability describes the suitability and transparency of the methods and analysis (Denzin and Lincoln 2000) which is referred to as an audit trail (Yilmaz, 2013). An audit trail describes the aim of the study, how the participants were recruited and how the data were collected and analysed (Thomas and Magilvy 2011). This chapter aims to address dependability by ensuring a clear and accurate account of the methods employed in the study. The lead researcher has previously experience with qualitative research at an undergraduate level and this research has subsequently been published in the British Journal of Occupational Therapy (Connolly et al 2014).

2.124 Confirmability

Confirmability is concerned with some degree of neutrality and to address this, the lead researcher kept a reflexive journal to record personal attitudes, opinions and perceptions prior to commencing the study and following completion of each interview. This aims to recognise the influence the researcher brings to the process and address any potential bias of the lead researcher by increasing awareness of one's own attitudes and beliefs on the research topic (Kuper et al 2008; Seale, 1999). The lead researcher is an occupational therapist who has worked in acute hospitals for six years with experience in the process of decision making capacity for independent living. An interest in the topic was generated with recent changes to legislation on decision making capacity.

2.125 Transferability

Finally, while the results of qualitative data are never generalisable they can be transferable to other groups (Yilmaz, 2013). A thick description of the participants and the events studied is required to ensure transferability or external validity (Yilmaz, 2013) which the next chapter will provide.

2.13 Conclusion

This chapter described the methods used to address the research aims and objectives of the study. The rationale for the study design, sampling method and participant recruitment has been described with an explanation of ethical considerations. The following chapter will present the results through description and illustration.

CHAPTER 3
RESULTS

3.1 Introduction

The following chapter presents the results of the analyses described in the data analysis section of chapter two. Thematic analysis identified three major themes which are outlined in Figure 3.1. This chapter will provide a broad overview of these themes and sub themes in relation to the research question: 'Occupational therapy practice in assessment of older person's decision making capacity to return home?'

3.2 Demographic Information

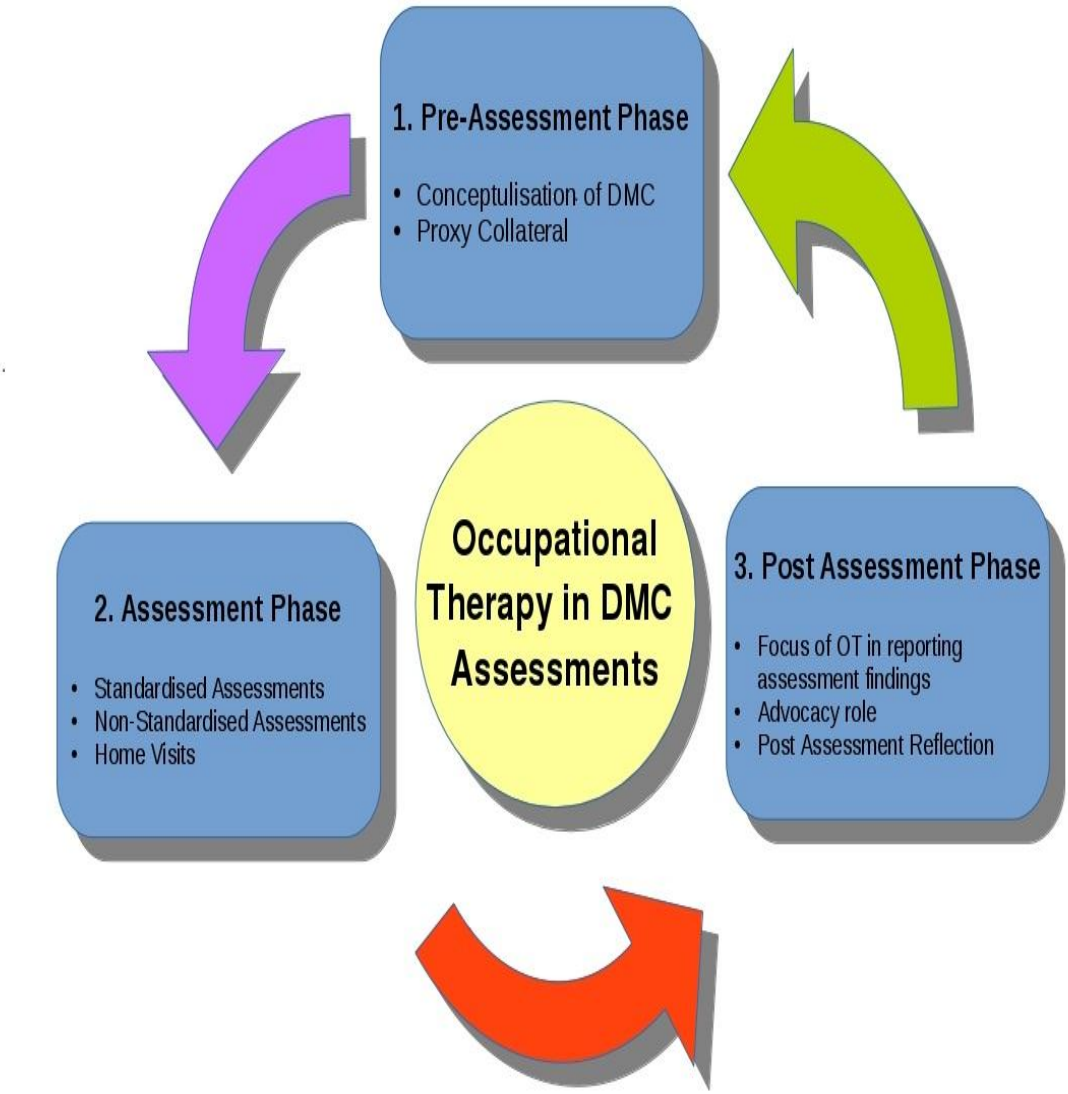
Interviews were completed with ten occupational therapists working in acute hospitals in Ireland. The mean duration of the interviews was 39.2 minutes (range was from 26 minutes to 62 minutes). All ten participants were female and worked in seven hospital sites (n= 7). The mean number of years since qualification was eight years. The mean estimated frequency of involvement in decision making capacity assessments was 2.2 times per month with one participant unable to provide an estimate. Table 3.1 details participants' demographics.

Table 3.1: Participant's Demographics

Participant	Gender	Work Location	Grade	Context of Practice	Years Qualified	Estimated Frequency Involved in DMC
P1	F	Dublin	Staff	Long Term Care	6	Once monthly
P2	F	Regional	Senior	Older Person's Rehabilitation	7	Once weekly
P3	F	Dublin	Senior	Acute Stroke	6	Once monthly
P4	F	Dublin	Staff	Geriatrics and General Medicine	6	Once monthly
P5	F	Dublin	Senior	Older Person's Rehabilitation	7	Once monthly
P6	F	Dublin	Senior	Acute hospital Emergency Department	6	Once weekly
P7	F	Regional	Senior	Acute over 65 years	11	Once weekly
P8	F	Dublin	Senior	Stroke Rehabilitation	9	Three times monthly
P9	F	Dublin	Senior	Day Hospital	8	Unable to estimate
P10	F	Regional	Senior	Acute Stroke	14	Once every two months

Abbreviations: DMC=Decision Making Capacity, F=Female, P=Participant

Figure 3.1: Graphical Representation of Themes and Sub-Themes



3.3 Theme One: Pre-Assessment

3.31 Conceptualisation of Decision Making Capacity

Prior to assessment participants created an understanding of decision making capacity (DMC) for independent living. Participants identified different types of decision making capacity and how in their experience a person could possess one type of decision making capacity and not another.

> P4 *"There is capacity for every single decision so they might have capacity to decide about going home but they might not have capacity to manage their finances."*

Participant 5 believed that decision making capacity may change over time.

> *P5 "It's not permanent and can be reversed; say a person was psychotic and they didn't have the capacity to agree to treatment, then it's not permanent and needs to be re-assessed at some point in the future."*

Five participants were aware of the Assisted Decision Making (Capacity) Act 2015.

> P2 "*It says that capacity is construed functionally and is decision specific and the patient's wills and preferences should be at the forefront and that capacity should be assumed unless the contrary is indicated."*

> P6 *"I have heard of it but I don't know much on it and I have received no training on it."*

For decision making capacity for independent living participants described the abilities a person required; an ability to understand the relevant information, to demonstrate insight into their abilities and limitations, problem solving skills and an awareness and acceptance of potential risks.

> P4 "*You have to be able to understand the information that you are given, weigh up the pros and cons of it".*

> P1 "*Insight is a huge factor for me, the ability to problem solve".*

P2 *"It's the ability to process and understand the risks that are associated with the decision* (to return home) *and then accepting those risks."*

3.32 Proxy Collateral

As part of their pre-assessment process, nine participants reported they contacted a next of kin. Liaising with family assisted participants in creating a picture of how the person was managing prior to their admission to hospital.

P2 "*I am trying to build up a picture on previous functioning and from the family's perspective if there was any deterioration, I would also ask about any premorbid concerns and the patients previous cognitive functioning".*

Family consultation also provided information on social supports. The level of assistance the person had at home and the amount of time the person spent alone had an impact in participant's reasoning of risk.

P3 "*It is very different if the person is very well supported by family and formal supports and the only demand placed on the person is to maintain their safety in between calls".*

A further reason to contact a next of kin was to allow the family the opportunity to express concerns they had regarding the person's safety.

P10 *"Family will tell you any safety concerns; that the person forgets to take her tablets or has locked themselves out of their home."*

3.4 Theme Two: Assessment Phase

Participants described their assessment practices in decision making capacity for independent living and explained the clinical reasoning which guided their decisions. Participants reported using a mix of assessment approaches; both standardised and non-standardised. The standardised approach consisted of standardised cognitive assessments to examine the person's cognitive abilities. The non-standardised approach consisted of observational assessments of personal care activities, domestic activities, instrumental activities of daily living and home visits.

3.41 Standardised Assessments

All participants reported they completed a standardised cognitive assessment and explained the factors that influenced their chose of cognitive assessment; including the person's age and educational level.

> P8 "*Choosing an appropriate cognitive assessment…..knowing that it's standardised for people over 65years old."*

> P9 *"If someone has a poor educational background I would choose a RUDAS* (Rowland University Dementia Screening Assessment)."

Five participants spoke in particular about the importance of the cognitive assessment measuring executive functioning.

> P3 "*I think it's important to look at executive functioning as it is the area of cognition that would determine someone's ability to plan, problem solve and their judgement skills."*

Executive functioning was considered necessary for the person to manage with the sometimes unpredictable events which may occur at home.

> P4 *"Can they problem solve and come up with solutions to the types of things that could happen at home. So what would you do if you smelled gas at home? What would you do if there as a fire? What if you were losing weight?"*

> P9 *"It is important look at executive functioning and problem solving abilities with novel tasks so if a light bulb goes will they know what to do or if an alarm goes off will they know what to do."*

Many participants spoke about the multidisciplinary team's over-reliance on the Mini Mental State Examination (MMSE) which led participants to choose alternative cognitive assessments. One participant explained that choosing an assessment that is less well known provided her with the opportunity to explain the meaning of the results in terms of functional ability to the multidisciplinary team.

> P4 "*Now we use different assessments;, the MOCA (*Montreal Cognitive Assessment*), ACE III (*Addenbrooke's Cognitive Examination III) *or the RUDAS*

so the medical team has to come to us and ask us what it means so we get the opportunity to explain it and say where the deficits are and what that all means for the patient."

The acute hospital can be a busy, distracting environment. Many participants described the modifiable factors they considered when completing a cognitive assessment such as assessment location. If possible participants completed the cognitive assessment in a quiet room away from the ward in order to minimise noise and optimise the person's performance.

P8 "*In my last job I would be doing a cognitive assessment with one patient in a 6 bedded ward and the patient beside her would be shouting the answers or someone else would be shouting at me 'be quiet'."*

P6 "*The ward is not an ideal context to assess someone, for a cognitive assessment we might bring them to a quieter room so one of the OT treatment rooms."*

Participants also described the optimal times for completing cognitive assessments and considered the morning times more conducive for enhancing cognitive performance.

P10 "*I would consider how alert or fatigued a patient is when I think of doing a cognitive assessment… And with visitors in the afternoon there are more distractions…. So I would try to schedule them* (cognitive assessments) *earlier in the day to get the best out of the patient."*

When analysing the results from cognitive assessments, participants considered the results in terms of the impact cognitive abilities may have on functional performance.

P2 *"I will relay cognitive* (assessment) *scores but I focus on how that impacts on function…. So I'm not talking about cognition in the broad sense, I talk about domains; executive function, memory, attention but then I try to pin point exactly the risks that came from my assessments and then try to look at the likely implications of these. So if it is an attention deficit then how that impacts on safety and function in the home".*

3.42 Non-Standardised Assessments

All ten participants stressed the importance of completing a non-standardised assessment which was an observational assessment of the individual's functional ability.

> P2 "*I think the crucial piece is that there is always a functional assessment completed in tandem with a* (standardised) *cognitive assessment."*

All participants reported that non-standardised assessments should include an evaluation of Instrumental Activities of Daily Living (IADL's). Participants explained that ADL tasks did not sufficiently challenge the person whereas IADL tasks required a greater range of cognitive skills.

> P10 "*Then I want to complete a novel task, a personal care assessment is not really a novel task so it won't give you lot of information".*

Participants reported that non-standardised assessments allowed them to observe how a person's cognitive deficits were impacting on their functional abilities. The focus during these observations was on the person's cognitive abilities of planning, sequencing, insight, safety and judgement.

> P8 "*Look at how they carry over information from one session to another and look at their safety within all of these tasks, so, are they just dragging the* (rollator) *frame around the kitchen?"*

> P10 *"During the kitchen assessment I would try to assess their insight; asking them to comment on their performance; Is it going well and why? Is it not going well and why?"*

However the task needed to be relevant to the person in order to adequately inform the assessment process.

> P9 "*So if someone didn't cook for themselves at home then I don't see the relevance in completing a kitchen assessment if they have meals on wheels or have home help as I do not feel it is telling me anything."*

In order to assess the person in an environment that reflected the home environment participants adapted and graded the activity. This assisted in providing a more accurate picture of how the person would manage at home.

P1 "*Well I think you can adapt an environment as much as possible to try and set it up like the person's home environment…….if it is a different kettle that they use at home, then you adapt it in the hospital.".*

P2 "*So I add as many distractions as I can in order to reflect, to some degree, what it may be like in the home environment*."

One of the participants has no facilities to complete a kitchen assessment in her practice context but emphasised the importance of assessing the person's cognitive abilities in an everyday task. This participant explained that she brings the person to the hospital shop to assess instrumental activities of daily living.

P4 "*I try to bring them to the shop in order to look at money management, their topographical orientation, their behaviours and problem solving."*

3.43 Home Visits

The acute hospital environment may have an impact on a person's functional abilities especially those with a cognitive impairment. Participants reported that people usually performed better in their own environment and a home visit enabled participants to assess this.

P5 *"It's important to see how they are managing at home and I think you have to assess someone there if you want to be accurate and thorough."*

P10 "*You need to look beyond the acute hospital; Is it the acute environment that is impacting on their ability and in that case you need to complete a home visit and assess them in their own environment".*

Six participants reported they would carry out a home visit. Four participants reported they were unable to complete home visits in their current role.

P7 *"Yes I would consider a home visit but in my current area unfortunately we do not complete home visits."*

Participants explained that a home visit provided a more detailed picture of the person's functional abilities. A specific focus on the home visit was to assess instrumental

activities of daily living such as telephone use, medication management and accessing the community.

> P2 *"From a cognitive perspective I try to focus on IADL's. So I discuss and assess medication management… they would have their pill boxes and prescriptions at home and so I would try to assess their ability to manage this".*

> P9 "*Use of alarms like pendant alarms and…. telephone….. And if someone calls to the door does the person automatically open the door and let them in? Can they find their local shop? Can they walk to it? Can they find their way back home?"*

Participant 6 reported that a home visit enabled her to assess areas of concern that family may have highlighted which could not be assessed in the hospital such as the person's ability to manage their gas cooker.

> *P6 "I would complete a home visit if the family had very specific concerns about things that were happening in the home context."*

Participant 9 explained that home visits allowed her to evaluate concerns highlighted from the hospital assessments.

> P9 "*I think if your concerns* (from hospital assessments) *are around safety and memory then it is important to review the patient in their own home, I think a kitchen assessment in the patient's own home is much more informative than one completed in the hospital".*

Four participants discussed factors that influenced their clinical decision to complete a home visit namely borderline cases and time constraints. Participant three explained that home visits were beneficial in cases where she required additional information.

> P3 "*There have been cases where it has been very border line and I have done a home visit….If I feel I need a little more context".*

Participants explained the time constraints placed on them in acute hospitals due to busy caseloads. As a result careful consideration was required prior to completing a home visit as it may take three hours to complete.

P6 “In *the acute setting you really need to weigh up how you are using your time especially with home visits and you have to have your justification for those cases.”*

Following the home visit three participants described how they would call to the individual after the home visit to discuss their perspective on the outcome of the visit. This information assisted participants in examining the individual’s level of insight.

P5 “*I will call in to the person after the visit and try and ask them how they feel it went, what went well and what didn’t because that tells me even more information.”*

3.5 Theme Three: Post-Assessment Phase

Once all assessments were completed, participants used the results to make their recommendations. Participants advised how these recommendations were reported to the multidisciplinary team.

3.51 Focus of Occupational Therapy in Reporting Assessment Findings

Participants reported that the purpose of the occupational therapy assessment was not to determine if the person possessed decision making capacity to live independently or where their future care needs should be met.

P9 *“I don’t feel it is our role to determine if a person does or doesn’t have capacity.”*

P10 *“I would never make a decision that a person needs to go to a nursing home.*

Participants identified how assessment findings are reported in terms of the person’s current functional ability and the level of assistance they would require with all activities associated with independent living.

P1 *“We relay this functionally such as ’they cannot enter the property, they cannot sequence functional tasks’.*

P9 *“I recommend the level of support the patient requires so I may feel that they would benefit from three visits a day for meal preparation, or, I could recommend*

that they require 24 hour supervision".

All participants explained that recommendations were documented in the medical chart.

P10 "*I document all in the medical chart but I have a feeling that it is not always read."*

Participants also endeavoured to liaise with the multidisciplinary team in person either at weekly case conferences or by meeting them on the ward.

P3 "*I would usually link in with the Medical Social Worker and the medical team".*

Two participants spoke of the challenges in communicating with the multidisciplinary team when there is no weekly team meeting.

P6 "*I feel it depends what speciality the patient is under in terms of how the team works together. So for example in care of the older person there are ward rounds and weekly meetings so there is a really close network in which to feed the information back but then in the general medicine wards you would have to bleep the team and make more of an effort to get on to them."*

P5 "*When I was on the general medicine wards you might never see the medical team."*

Once the assessment findings were communicated to the medical team, the medical Consultant completed a DMC assessment.

P10 " *It (*DMC assessment*) is determined by the medical Consultant, they take into account what the family have said and they would consider cognitive assessment results and our input around function and home visit outcomes."*

3.52 Advocacy Role

Post assessment participants reflected on their role in the process of decision making capacity for independent living and the need for further training and support. Acting as an advocate for the person was a role many participants identified with. Participants spoke about ensuring the person's wishes were acknowledged and if the person was

unable to return home, that they were involved in the process of choosing their new home.

> P6 "*In terms of advocating for the patient that often falls to OT and I think that is what we often bring to the table; so what it is the patient wants and what is important to them?"*

> P7 "*If it is decided that they will go to long term care perhaps the patient can decide which nursing home they will live in and I was always the person advocating for that."*

Participants also described how on some occasions they have acted as an advocate for the person to ensure that s/he was informed and understood what was happening.

> P1 "*I have a patient currently with aphasia in the long term care ward and she has a few sounds not words…. and she wished to go home. So we organised a session with speech and language therapy and explained it all to her. And she understands now that she cannot return home but she is very worried that her family are in her house and there is an elder abuse issue going on. But she had been moved from three different wards in the hospital and then to the hospital long term care ward and for four years no one explained to her what was happening."*

3.53 Post Assessment Reflection

When reflecting on the process participants reported there was no training at undergraduate level and limited training in their current position on their role in decision making capacity assessments for independent living. As a result, early in their careers participants described feeling overwhelmed and often unsupported when involved in these cases.

> P5 "*This is a huge decision and certainly when I started out I found it overwhelming that everyone was looking to me for answers."*

> *P3 "You need training or senior support (as a novice therapist) and very often that was not available".*

Participants explained their confidence has grown with increasing experience and involvement in decision making capacity cases and this has helped to develop their clinical reasoning.

> P10 *"The more experience I have gained the more confident I am with my clinical reasoning."*

As a result of this increased confidence in clinical reasoning participants reported they are less paternalistic and consider more positive risk taking. Participants explained that early in their careers they may have been over cautious in their recommendations.

> P3 ***"****I am taking on board a lot more positive risk taking and the will and preferences of the patient. I am not underestimating someone's ability to make their own decisions as much as I was. I feel I was over cautious as a novice therapist."*

> P5 *"There is risk associated with everything and perhaps we are all a bit too paternalistic and place safety too highly above the patient's wishes."*

Participants identified that education on their role in the process is an area for further education and training.

> P6 *"There are always questions in the department with regard capacity and the same issues keep coming up. I think it is a bit if a grey area so we are all very much trying to help each other out but it would be great to get some formal training on the role of OT in the process."*

3.6 Conclusion

Ten occupational therapists from a variety of practice context were interviewed. Pre-assessment participants created an understanding of decision making capacity for independent living. Participants identified the decision specific and temporal nature of decision making capacity. Participant's explained an individual needed to understand all of the relevant information and manipulate the information to identify and accept potential risks. Participants employed a mixed assessment approach using both standardised and non-standardised assessments of which the latter were reported as the most informative. Due to concerns regarding the ecological validity of hospital based

assessments, if possible participants completed a home visit to ascertain the individual's abilities in their own environment. Assessment findings were communicated in the medical chart and verbally to the medical team. Finally participants discussed their role in the process which was to report assessment findings in terms of the person's functional ability and the level of assistance they would require at home. Another role participants identified with was acting as an advocate for the person to ensure the person's wishes were acknowledged and that the person was involved in the process as much as possible. Further training and education was identified by all participants in conjunction with the development of practice guidelines for occupational therapists in decision making capacity cases. The next chapter will discuss the key implications of these findings and make recommendations for future research.

CHAPTER 4
DISCUSSION

4.1 Introduction

Decision making capacity describes an individual's ability to make a decision and is composed of four constructs; the ability to understand the information relevant to the decision, to appreciate the relevance to one's own situation, to use that information as part of the decision making process and to communicate the outcome of the decision (Emmett et al 2013). In December 2015, the Assisted Decision Making (Capacity) Act 2015 was launched in Ireland. The Act provides reform of the law pertaining to individuals who require or may require assistance in exercising their decision making capacity either currently or in the future. The Act describes a functional approach to the assessment of an individual's decision making capacity (Assisted Decision Making (Capacity) Act, 2015). The aim of the current study was to explore the practices of hospital occupational therapists in the process of determining older person's decision making capacity to live independently. The three objectives were;

- To determine occupational therapists understanding of decision making capacity for independent living.
- To ascertain the assessments completed by occupational therapists in decision making capacity for independent living.
- To explore the outcomes of assessment findings.

This chapter will discuss the interview findings in relation to the study aims and objectives and will include limitations of the study and recommendations for future research.

4.2 Participant Profile

For this study ten occupational therapists working in acute hospitals with older adults volunteered and in total seven acute hospitals sites were represented. All participants who volunteered to take part in the study were female as there are a greater proportion of female occupational therapists than male (Parish et al 1990). Participant's clinical

experience ranged from six to fourteen years and eight of the participants were practicing at a senior grade.

4.3 The Pre Assessment Phase

Prior to the assessment process participants described their understanding of decision making capacity. Participants reported that an individual's decision making capacity may change over time and that a separate assessment was required for every decision. In December 2015, the Assisted Decision Making Bill 2013 was passed through legislation and has become the Assisted Decision Making (Capacity) Act 2015. Although only half of the participants reported some knowledge of the Act all participant's description of decision making capacity was similar to the Act's description. Considering the recency of the Act perhaps participants are not yet familiar with its content. However, as part of legislation it is imperative that health care professionals receive training on the Act and the implications it may have on their practice. As education on the Act is disseminated among members of the multidisciplinary team future research could examine clinician's knowledge and understanding of the Act and its influence on their practice.

Participants described the construct of decision making capacity as multifaceted; requiring an individual to understand and manipulate information, possess insight into their abilities and limitations, identify and accept potential risks and demonstrate problem solving. When this description of decision making capacity is compared to the description in the Act there are many similarities. The Act explains that an individual needs to understand all of the information relating to the decision, retain it for long enough to make a choice, weigh up the information as part of the decision making process and express a choice (Assisted Decision Making (Capacity) Act, 2015). Wong (1999) reported that an individual required insight to appreciate the relevance of the information to their own situation which was also highlighted by participants in the current study. It appears that participant's understanding of decision making capacity is reflective of current legislation which is important as participants used their understanding of decision making capacity to guide the assessments process.

Participants reported that the pre-assessment phase involved building a detailed picture of the individual prior to admission. As part of this participants discussed the importance of consulting with a next of kin. These consultations were viewed as an opportunity to enquire about the individual's social supports, pre-admission functioning and identify specific safety concerns. These findings are similar to a study by Jette et al (2003) who explored the decision making processes for physical and occupational therapists in a US rehabilitation site. The study reported that information used for discharge decision making was collected from four key areas; the individuals functional ability, their wishes, their ability to participate in therapy and their context. The individual's context was comprised of their social and physical environment. An individual's level of social supports strongly influenced therapists reasoning when discharge planning as they considered the ability of the social environment to meet the individual's needs.

Concerns expressed by family members namely safety issues such as unsafe use of a gas cooker were used by participants to individualise the assessment process. Family involvement in this manner appears to have ensured assessments were focussed on pertinent areas of concern. While there appears to be limited literature exploring family involvement in decision making capacity assessments, participants in the current study considered it of benefit to incorporate family in the pre-assessment process. Macciocchi and Stringer (2001) advised that if possible family should be consulted in decision making capacity assessments as family's information on how the individual was previously managing may assist in the determination of risk and harm. Furthermore involving family acknowledges their concerns which may help to reduce their anxiety regarding the process. However, an important factor to note is the time associated with gaining collateral from multiple sources. In an acute hospital allocating time to liaise with family and community colleagues may be challenging especially considering the frequency with which participants were involved in decision making capacity cases. While the merits of building a detailed picture of the individual was stressed by all participants if adequate staffing resources are not available this may not always be feasible. Considering the significance of the outcome of decision making capacity assessments insufficient time for therapists may have impact on the breadth of collateral gained. While no practice guidelines for occupational therapy in decision making

capacity for independent living currently exist, their development may assist in acknowledging the importance of gaining a detailed collateral history.

4.4 The Assessment Phase

The results of the current study indicated that participants employed both standardised and non-standardised assessments in their practices for decision making capacity for independent living. Moberg and Rick (2008) recommended a multipronged assessment process as there is no one determinant of decision making capacity. The multimodal assessment reported in the current study acknowledges the multidimensional nature of decision making capacity. Participants described how standardised assessments allowed evaluation of an individual's cognitive abilities and typically used cognitive assessments that took 10-15 minutes to administer. Non-standardised observational assessments were used to examine an individual's functional abilities with areas such as meal preparation and medication management. Assessments took place at various times of the day and in different contexts to ensure the assessments were representative of the individual's abilities. These findings are consistent with those of speech and language therapists involved in decision making capacity for individuals with aphasia (Aldous et al 2014). Similarly, it was demonstrated that speech and language therapists administered both formal and informal assessments to guide their clinical reasoning and inform their recommendations. An individualised assessment process may provide a more accurate picture as it may include assessment of a wider range of skills that standardised assessments alone may not provide. A mixed assessment approach may be more flexible and allow for consideration of influencing factors such as time of the day and the hospital environment. Perhaps as the process of decision making capacity for independent living is intricate (Moye et al 2006) it necessitates a mixed assessment approach.

Participants identified specific standardised assessments which they used to evaluate cognitive ability such as the Addenbrooke's Cognitive Examination III (ACE III), Montreal Cognitive Assessment (MOCA) and Rowland University Dementia Assessment Scale (RUDAS). Holm and Mu (2012) explored occupational therapists' perceptions on discharge planning with the elderly. While the study did not specifically

relate to decision making capacity there were similarities in therapists reasoning of important cognitive components for independent living. Consistent with these findings participants in the current study considered the cognitive construct of executive functioning as a particularly important element for independent living. For this reason participants were more likely to choose a cognitive assessment that incorporated elements of executive functioning.

Particular reference was made by participants to not using the Mini Mental State Examination (MMSE) due to participant's perceived over-reliance on this screen by multidisciplinary team members in the past. This reduced the need for multidisciplinary team discussion on the findings of the cognitive assessment. This in itself may not be a particularly valid reason for not using the MMSE. However previous research has identified problems with the validity of the MMSE in decision making capacity assessments and the evidence does not seem to support its validity in determining decision making capacity (Etchells et al 1997; Allen et al 2003; Kim and Caine 2002). This finding indicates a need for further research to identify which cognitive assessments are most appropriate for decision making capacity assessments.

When analysing the results from cognitive assessments, some participants stated that they focussed on the individual's performance within specific cognitive domains such as memory or attention rather than the overall numerical score. Perhaps this is based on participant's clinical experience that poor scores on cognitive assessments may not reflect an individual's functional ability (Baum and Edwards 1993). Considering this and the multitudinous factors which may influence an individual's cognitive performance perhaps non-standardised assessments are more representative of an individual's cognitive and functional ability. It is interesting that the reported cognitive assessments participants administered were brief tools which were 10-15 minutes to administer rather than more time consuming cognitive batteries. Perhaps this is due to the time constraints of the acute hospital and supports the need for extra resources in decision making capacity assessments. However, further research is required to explore the reasons occupational therapists appear to use brief cognitive assessments.

Participants discussed factors they considered when completing cognitive assessments such as the individual's educational level, time of the day and the assessment environment. Participants believed that optimisation of performance could be achieved by completing assessments in the morning when an individual is more alert and in a quiet environment. It is acknowledged that many factors may influence an older person's cognitive performance; educational level, pain, mood, infection, medication side effects and fatigue (Lo, 1990; Cattarinich et al 2001). It seems that many of these factors were considered by participants when selecting and completing the cognitive assessment. This finding suggests that additional resources may be required in the hospital to accommodate for some of these factors and to optimise an individual's performance on cognitive assessments. This may include having dedicated rooms on the wards in which to complete cognitive assessments where there are minimal distractions.

Research has suggested that cognitive performance may be more appropriately measured through observation in everyday activities (Applegate et al 1990). This finding was reflected in the current study as participants placed a greater value on an individual's performance in non-standardised assessments than standardised cognitive assessments. The finding that observational evaluations are the most informative assessment tool to guide therapist's clinical reasoning is acknowledged in other research. Similarly, Ferguson et al (2010) reported that informal observation was viewed as the most important component of the assessment process for speech and language therapists in decision making capacity assessments.

In the current study cognitive deficits were perceived to have a greater impact on IADL's performance than on ADL performance. As such participants were more likely to select an IADL functional task such as meal preparation rather than an ADL task such as washing and dressing. For individuals with a cognitive impairment there is increasing evidence that performance on basic ADL's may remain intact as it is proposed that there is minimal reliance on cognitive processes for these tasks (Allaire et al 2009; Carswell and Eastwood 1993). One reason for this may be that an IADL task may use a greater range of cognitive processes and therefore cognitive deficits may be detected more quickly. In selecting more complex IADL tasks participants were able to

challenge the individual and observe a greater range of cognitive skills. This finding is contrary to that of Crennan and MacRae (2010) who examined occupational therapy practices in discharge planning and reported that occupational therapists in acute hospitals did not routinely assess performance in IADL's due to time resources. However although the current study was carried out in acute care IADL's were always assessed. Perhaps this difference indicates that IADL assessments may be more informative than ADL assessments in decision making capacity cases. This may be an area for consideration if practice guidelines for occupational therapists in this process are developed.

All participants questioned the ecological validity of hospital based assessments. Participants endeavoured to adapt the hospital environment as much as possible to reflect the home environment. Nonetheless participants reported that due to unfamiliarity of the hospital surroundings an individual's performance may not be truly reflective of their performance in the home environment. Other research has demonstrated that older individuals and their environments are interdependent and that the environment actively contributes to the daily functioning of an individual (Davies et al 2005). There is evidence to indicate that procedural memory for motor tasks is highly dependent on the environment and is enhanced by a familiar setting (Davies et al 2005). Therefore, if possible participants completed home visits to evaluate the individual performance within their own home. For decision making capacity assessments, Moberg and Rick (2008) advised that health professionals need to ascertain the extent to which the individual is meeting the demands associated with living independently. The authors recommended that this is completed through a direct observation of the individual in their own environment as the reliability of assessments completed in other contexts were questionable.

In addition to home visits providing a more accurate assessment of the individual's ability, they also offered the opportunity to assess a wider range of IADL's. In the current study a particular focus during home visits was on the individual's performance with activities that could not be assessed in the hospital environment. This included medication management, accessing the community and use of telephones and pendant

alarms. This finding suggests that the home environment offers the opportunity to assess a greater range of IADL's. By assessing a greater number of IADL's during home visits there is a greater breadth of assessment data to inform a person's decision making capacity assessment. This finding would suggest that where possible home visits should be completed in decision making capacity assessments and may form an important part of practice guidelines for occupational therapists involved in these cases. In cases where the hospital occupational therapist is unable to complete home visits as part of their role, primary care occupational therapists may be able to offer an assessment of the individual in their own home.

Home visits also enabled participants to assess those specific areas of concern that were highlighted by family or identified through hospital based assessments. Home visits were individualised by incorporating family collateral into the evaluation in the home environment. This may be an important benefit of home visits as specific areas of concerns could be assessed. Participants were also able to focus on particular issues that were highlighted during hospital assessments and observe the individual completing the same task in their own environment. There appears to be minimal literature examining the benefits of home assessments in decision making capacity for independent living. However considering the emphasis participants placed on home visits it is concerning that not all participants were able to complete home visits in their current role. The participants who could complete home assessments reported the time challenges associated with these visits as they can take up to three hours to complete. Practice guidelines for occupational therapist involved in decision making capacity for independent living may assist occupational therapists to justify the need for home visits and the time spent completing them. It may be worthwhile for future research to compare international practices for decision making capacity for independent living with Irish practices. This could help to establish a need for home assessments in these cases.

4.5 The Post Assessment Phase

Participants discussed the process after completing their battery of assessments. They described how post assessment all results were communicated in terms of the individual's functional ability and the level of assistance an individual would require for independent living. It was considered the role of occupational therapy to make recommendations on the level of assistance required with ADL's and IADL's rather than making a judgement on whether or not an individual can return home. Participants reported that they document the assessment results in the medical chart and report them verbally to the multidisciplinary team either at ward round or at weekly team meetings. It seems participants used two methods of communication to ensure that the multidisciplinary team was fully aware of the assessment results. However, two participants identified challenges in communicating to the multidisciplinary team as there were no weekly team meetings in their hospitals. In these instances the assessment results were documented in the medical chart only without team meetings. A study by Aldous et al (2014) reported that information gained through structured discussion with multidisciplinary team members contributed greatly to speech and language therapist's opinion of an individual's decision making capacity. This seems to suggest that team discussions are helpful to health care professionals in forming their clinical recommendations. Considering the breadth of assessments completed by participants in conjunction with collateral gained from family members a weekly team meeting may be a necessary forum to ensure team discussion.

Ferguson et al (2010) reported that speech and language therapists described their roles in decision making capacity for individuals with aphasia as an assessor and acting as an advocate for the patient. Participants in the current study also identified with acting as an advocate for the individual and reported ensuring the individual's wishes are sought and acknowledged by the multidisciplinary team. The Assisted Decision Making (Capacity) Act 2015 emphasises the importance of establishing the will and preferences of the individual; "the intervener in making an intervention….shall give effect…. to the past and present will and preferences of the relevant person, in so far as that will and those preferences are reasonably ascertainable" (Assisted Decision Making (Capacity) Act 2015). From the current study it seems a potential role of occupational therapy in decision making capacity cases may be to establish the individual's will and preferences

prior to assessment. A further advocacy role which participants identified with was ensuring the individual was informed throughout the process and giving them the power to make as many decisions as they could. One example of this was when the individual was deemed to lack decisional capacity for independent living; participants ensured the individual was involved in choosing their nursing home. Considering the limited available literature on occupational therapy in decision making capacity assessments it appears there is a need for the development of practice guidelines for occupational therapists. An integral part of these guidelines may be the multifaceted role of occupational therapy in decision making capacity assessments for independent living. However, prior to this a larger study is required to confirm the role of occupational therapy in decision-making capacity. It would also be important for future research to explore the role of other multidisciplinary team members in decision making capacity assessments.

Post assessment, participants appeared to reflect on their involvement in the decision making capacity process. Some participants explained that early in their careers they were very focussed on an individual's safety. This was reflected in their sometimes over cautious recommendations on the level of assistance an individual would require at home. This result is similar to a study that explored occupational therapists clinical reasoning when prescribing powered scooters for clients (Maywald and Stanley 2014). Novice occupational therapists were more likely to experience anxiety over potential risks that clients could encounter when using their scooters. However, with increased experience therapists accepted that risk cannot be eliminated and were more likely to trial powered mobility with their clients. In the current study, one explanation for participants' over cautious practice early in their careers may be a lack of formal training on decision making capacity. Limited knowledge on decision making capacity and the supporting legislation may have increased participant's anxiety in these cases. This may have fostered a more conservative approach in their recommendations. As highlighted by Ferguson et al (2010) and Aldous et al (2014) speech and language therapists considered their previous training in decision making capacity insufficient and recommended further education. All participants in the current study reported the need for further training in decision making capacity. This suggests that current undergraduate and clinical training are insufficient to equip participants with the

necessary knowledge and skills for involvement in the decision making capacity process. Further research is required to determine the content and optimal timing for this education.

Another explanation for this finding may be novice therapist's lack of previous clinical experience. Novice therapists have limited experiences to draw upon which may be challenging when determining level of risk and making recommendations. This limited repertoire of experience may mean novice therapists are more likely to be over cautious when determining the level of assistance an individual needs. Therefore early in their careers participants may have had insufficient supervision to help create their conceptualisation of decision making capacity and an assessment framework. It seemed as participants were more frequently involved in decision making capacity cases they adopted a less paternalistic perspective. It would appear that with increasing involvement in decision making capacity cases participants increased their understanding of decision making capacity and developed a framework to guide their assessments. This finding suggests that novice therapists with limited experience in decision making capacity cases may require support and mentoring from more experienced therapists. It may also indicate that involvement in decision making capacity cases should be limited until the therapist has gained sufficient clinical experience. Further research is needed to confirm this possibility.

4.6 Study Limitations

- As with all qualitative studies the results are not generalisable (Yilmaz, 2013). The sample size of the study was ten occupational therapists from seven hospital sites; a limitation of the study was the relatively small sample size and only seven hospital sites.
- All participants were female and participant's clinical experience varied from six to fourteen years which may be considered a relatively narrow range of experiences.
- The lead investigator analysed and coded all transcripts and only three transcripts were coded by an external validator which may represent another limitation of the study.

- As the lead investigator is an occupational therapist, participants may have been less inclined to disclose their personal perspectives regarding their practices in decision making capacity.
- As the lead investigator is an 'insider' she may have projected her own biases onto the study findings although methodological steps were taken to avoid this.

4.7 Recommendations for Future Research

As there is limited literature on decision making capacity for independent living there are many opportunities for future research which would include;

- A comparison of the practices of senior and staff grade occupational therapists in decision making capacity for independent living.
- Health care professional's knowledge and understanding of the Assisted Decision Making (Capacity) Act 2015.
- The influence of the Assisted Decision Making (Capacity) Act 2015 on the practices of occupational therapists in decision making capacity for independent living.
- An exploration of the role of the multidisciplinary team members in decision making capacity for independent living.
- Occupational therapist's clinical reasoning in assessing cognitive performance for decision making capacity for independent living.
- A comparison of national and international practices of occupational therapists in decision making capacity for independent living.
- The role of occupational therapy in decision making capacity for financial/consent to treat/testimonial decision making capacities.
- An exploration of the practices of occupational therapists in decision making capacity for independent living with individuals with an intellectual disability.

4.8 Conclusion

The results of this study suggest that involvement in decision making capacity for independent living is a cyclical process incorporating three stages. In the first stage, participants sought to create an understanding of decision making capacity and the individual. The pre-assessment phase appears to have acted as a template for the approach used in the second stage; the assessment phase. The results indicate that occupational therapists use a mix of standardised and non-standardised assessments of which the latter were considered the most informative and relevant part of the assessment. The nature and context in which non-standardised assessment were completed formed part of participant's clinical reasoning. IADL's were chosen as they were considered more cognitively demanding and more representative of the individual's ability. The home environment was considered the optimal environment in which to complete functional assessments as participants questioned the ecological validity of the hospital environment. The third stage of the process involved documenting and relaying the assessment results to the multidisciplinary team.

Participants considered it was the role of occupational therapy to discuss the results in terms of the individual's functional abilities and limitations and the level of assistance they would require if discharged home. Acting as an advocate on behalf of the individual was another role many participants identified with. Post assessment, participants reflected on their involvement in the process and incorporated the knowledge and skills they had gained into their conceptualisation of decision making capacity which was the first stage; the pre-assessment phase. Involvement in decision making capacity appears to represent a cyclical process with each stage of the process guiding the next stage. Given the recent enactment of the Assisted Decision Making (Capacity) Act (2015), clear guidelines are required on the role of various health professionals in determining a person's ability to make informed decisions regarding their safety and welfare. It is hoped that this exploratory study has begun to identify the contribution of occupational therapists to the process, however a larger sampled study is required to validate and elaborate on these findings.

CONCLUSION

Irelands older population are growing and associated with increasing age are cognitive and functional decline. Cognitive and functional decline are linked to decreased decision making ability which can necessitate the need for a decision making capacity assessment. In the acute hospital occupational therapists are frequently involved in decision making capacity assessments yet there is very limited literature that examines their practices in this process. Consequently, this study sought to explore this issue and the findings provide an insight into the practices of ten occupational therapists working in acute hospitals in Ireland. It appears that occupational therapy involvement in decision making capacity assessments represents a cyclical process consisting of three stages; pre-assessment, assessment and post-assessment.

The pre-assessment phase assisted participants in forming a conceptualisation of decision making capacity and the individual prior to their hospital admission. This stage seems to have highlighted important areas to assess and acted as a template for the next stage; the assessment phase. All participants identified using a mixed assessment approach consisting of both standardised and non-standardised assessments. The standardised approach consisted of cognitive assessments to evaluate an individual's cognitive ability. This was considered important as it highlighted cognitive concerns which were focussed upon during the non-standardised assessments. These non-standardised observational assessments provided an opportunity to examine how an individual's cognitive abilities impacted on their functional performance. The tasks selected were IADL activities such as meal preparation as participants agreed that in choosing a novel or more cognitively demanding task, it assisted in forming a more accurate picture of the individual's true abilities. Participants questioned the ecological validity of hospital based assessments and if possible completed home visits.

Once all assessments were completed participants described how the results were relayed to the medical team in terms of the individual's functional ability and the level of assistance they would require at home. Participants recognised this as their role in the process and also identified acting as an advocate as another role. Post assessment,

participants reflected on their involvement in these cases and appear to use the knowledge and skills gained to help form their understanding of decision making capacity which was the first stage of the process. It seems that increased frequency and experience in these cases has assisted participants in their conceptualisation of decision making capacity and in creating an assessment framework. It appears that coaching from more experienced occupational therapists may assist novice therapists with limited experience in this process as all participants identified further training as a professional need. Limitations of this study include the relatively small sample size and that only seven hospital sites were represented. As there is very limited literature on this topic, future studies could examine occupational therapy practices with other client groups such as intellectual disability or indeed in other service areas such as primary care. It may also be worthwhile to explore the practices of other multidisciplinary members in the process.

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References

Aldous, K., Tolmie, R., Worrall, L. and Ferguson, A. (2014) 'Speech-language pathologists' contribution to the assessment of decision-making capacity in aphasia: A survey of common practices', *International Journal of Speech-Language Pathology*, *16*(3), pp231-241.

Allaire, J. C., Gamaldo, A., Ayotte, B. J., Sims, R. and Whitfield, K. (2009) 'Mild cognitive impairment and objective instrumental everyday functioning: the everyday cognition battery memory test, *Journal of the American Geriatrics Society*, *57*(1), pp120-125.

Allaire, J. C. and Marsiske, M. (2002) 'Well-and ill-defined measures of everyday cognition: relationship to older adults' intellectual ability and functional status', *Psychology and Aging*, *17*(1), pp101-115.

Allen, R. S., DeLaine, S. R., Chaplin, W. F., Marson, D. C., Bourgeois, M. S., Dijkstra, K. and Burgio, L. D. (2003) 'Advance care planning in nursing homes: correlates of capacity and possession of advance directives', *The Gerontologist*, *43*(3), pp309-317.

Anderson, C. (2010) 'Presenting and evaluating qualitative research', *American Journal of Pharmaceutical Education*, *74* (8) pp1-7.

Atwal, A., Spiliotopoulou, G., Stradden, J., Fellows, V., Anako, E., Robinson, L. and McIntyre, A. (2014) 'Factors influencing occupational therapy home visit practice: a qualitative study', *Scandinavian Journal of Occupational Therapy*, *21*(1), pp40-47.

Baum, C. and Edwards, D. F. (1993) 'Cognitive performance in senile dementia of the Alzheimer's type: The kitchen task assessment', *American Journal of Occupational Therapy*, *47*(5), pp431-436.

Bowling, A. (2014) *Research Methods in Health: Investigating Health and Health Services.* Maidenhead: Open University Press.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, *3*(2), pp77-101.

Breden, T. M. and Vollmann, J. (2004) 'The cognitive based approach of capacity assessment in psychiatry: A philosophical critique of the MacCAT-T', *Health Care Analysis*, *12*(4), pp273-283.

Brindle, N. and Holmes, J. (2004) 'Capacity and coercion: dilemmas in the discharge of older people with dementia from general hospital settings', *Age and Ageing*, *34*(1), pp16-20.

Britten, N. (1995) 'Qualitative interviews in medical research', *British Medical Journal*, *311*(6999), pp251-253.

Brown, C. L. and Finlayson, M. L. (2013) 'Performance measures rather than self-report measures of functional status predict home care use in community-dwelling older adults', *Canadian Journal of Occupational Therapy*, *80*(5), pp284-294.

Bryman, A. (2012) *Social Research Methods*. Oxford University Press.

Capozzi, J. D. and Rhodes, R (2002) 'Assessing a patient's capacity to refuse treatment', *The Journal of Bone and Joint Surgery*, *84*(4), pp691-693.

Carroll, D. W. (2010) 'Assessment of capacity for medical decision making', *Journal of Gerontological Nursing*, *36*(5), pp47-52.

Carswell, A. and Eastwood, R. (1993) 'Activities of daily living, cognitive impairment and social function in community residents with Alzheimer disease', *Canadian Journal of Occupational Therapy*, 60(3), pp130-135.

Carter, S. and Henderson, L. (2005) *Approaches to Qualitative Data Collection in Social Science. Handbook of Health Research Methods: Investigation, Measurement and Analysis.* Maidenhead: Open University Press, McGraw-Hill Education.

Cattarinich, X., Gibson, N. and Cave, A. J. (2001) 'Assessing mental capacity in Canadian aboriginal seniors', *Social Science and Medicine, 53*(11), pp1469-1479.

Christensen, K., Haroun, A., Schneiderman, L. J. and Jeste, D. V. (1995) 'Decision-making capacity for informed consent in the older population', *Journal of the American Academy of Psychiatry and the Law Online, 23*(3), pp353-365.

Cohn, E.S. (2014) *Willard and Spackman's Occupational Therapy, 12th Edition.* Philidelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Connolly, D., McNally, A., Moran, D. and Ryan, M. (2014) 'Fatigue in systemic lupus erythematosus: impact on occupational participation and reported management strategies', *The British Journal of Occupational Therapy, 77*(7), pp373-380.

Coombes, L., Allen, D., Humphrey, D. and Neale, J. (2009) In-depth interviews. In: *Research Methods for Health and Social Care*. (Neale, J., ed), New York, Palgrave Macmillan, pp197-210.

Crennan, M. and MacRae, A. (2010) 'Occupational therapy discharge assessment of elderly patients from acute care hospitals', *Physical & Occupational Therapy in Geriatrics, 28*(1), pp33-43.

Creswell, J. W. and Miller, D. L. (2010) 'Determining validity in qualitative inquiry', *Theory into Practice, 39*(3), pp124-130.

Critical Appraisal Skills Program (CASP) for Qualitative Research. http://www.bettervaluehealthcare.net/wp-content/uploads/2015/07/CASP-Randomised-Controlled-Trial-Checklist_2015.pdf [Accessed 2 September 2015].

Curtin, M. and Fossey, E. (2007) 'Appraising the trustworthiness of qualitative studies: guidelines for occupational therapists', *Australian Occupational Therapy Journal, 54*(2), pp88-94.

Darzins, P. (2010) 'Can this patient go home? Assessment of decision-making capacity', *Australian Occupational Therapy Journal*, *57*(1), pp65-67.

Davis, L. A., Hoppes, S. and Chesbro, S. B. (2005) 'Cognitive-communicative and independent living skills assessment in individuals with dementia: A pilot study of environmental impact', *Topics in Geriatric Rehabilitation*, *21*(2), pp136-143.

Dekkers, W. J. (2001) 'Autonomy and dependence: chronic physical illness and decision-making capacity', *Medicine, Health Care and Philosophy*, *4*(2), pp185-192.

Denzin, N.K. and Lincoln, Y.S. (2000) *Handbook of Qualitative Research, 2nd Edition.* SAGE Publications.

Department of Justice and Equality (2015) Assisted Decision Making (Capacity) Act 2015, Available at: http://www.oireachtas.ie/documents/bills28/acts/2015/a6415.pdf [Accessed 2 January 2016].

DiCicco-Bloom, B. and Crabtree, B. F. (2006) 'The qualitative research interview', *Medical Education*, *40*(4), pp314-321.

Diehl, M., Willis, S. L. and Schaie, K. W. (1995) 'Everyday problem solving in older adults: observational assessment and cognitive correlates', *Psychology and Aging*, *10*(3), pp478-491.

Emmett, C., Poole, M., Bond, J. and Hughes, J. C. (2013) 'Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards', *International Journal of Law and Psychiatry*, *36*(1), pp73-82.

Etchells, E., Darzins, P., Silberfeld, M., Singer, P. A., McKenny, J., Naglie, G. and Strang, D. (1999) 'Assessment of patient capacity to consent to treatment', *Journal of General Internal Medicine*, *14*(1), pp27-34.

Etchells, E., Katz, M. R., Shuchman, M., Wong, G., Workman, S., Craven, N. K. C. J. and Singer, P. A. (1997) 'Accuracy of clinical impressions and Mini-Mental State Exam scores for assessing capacity to consent to major medical treatment: comparison with criterion-standard psychiatric assessments', *Psychosomatics, 38*(3), pp239-245.

Fereday, J. and Muir-Cochrane, E. (2008) 'Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development', *International Journal of Qualitative Methods, 5*(1), pp80-92.

Ferguson, A., Duffield, G. and Worrall, L. (2010) 'Legal decision-making by people with aphasia: Critical incidents for speech pathologists', *International Journal of Language and Communication Disorders, 45*(2), pp244-258.

Fitten, L. J. and Waite, M. S. (1990) 'Impact of medical hospitalization on treatment decision-making capacity in the elderly', *Archives of Internal Medicine, 150*(8), pp1717-1721.

Fricke, J. and Unsworth, C. (2001) 'Time use and importance of instrumental activities of daily living', *Australian Occupational Therapy Journal, 48*(3), pp118-131.

Ganzini, L., Volicer, L., Nelson, W. and Derse, A. (2003) 'Pitfalls in assessment of decision-making capacity', *Psychosomatics, 44*(3), pp237-243.

Hansen, E.C. (2006) *Successful Qualitative Health Research: A Practical Introduction.* New York: Open University Press.

Hazelton, L. D., Sterns, G. L. and Chisholm, T. (2003) 'Decision-making capacity and alcohol abuse: clinical and ethical considerations in personal care choices', *General Hospital Psychiatry, 25*(2), pp130-135.

Holm, S. E. and Mu, K. (2012) 'Discharge planning for the elderly in acute care: The perceptions of experienced occupational therapists', *Physical & Occupational Therapy in Geriatrics, 30*(3), pp214-228.

Jette, D. U., Bacon, K., Batty, C., Carlson, M., Ferland, A., Hemingway, R. D. and Volk, D. (2003) 'Evidence-based practice: beliefs, attitudes, knowledge, and behaviours of physical therapists', *Physical Therapy*, *83*(9), pp786-805.

Jubb, M. T. and Evans, J. J. (2015) 'An investigation of the utility of the Addenbrooke's Cognitive Examination III in the early detection of dementia in memory clinic patients aged over 75 years', *Dementia and Geriatric Cognitive Disorders*, *40*(3-4), pp222-232.

Karlawish, J. (2008) 'Measuring decision-making capacity in cognitively impaired individuals', *Neurosignals*, *16*(1), pp91-98.

Kim, S. Y., Karlawish, J. H. and Caine, E. D. (2002) 'Current state of research on decision-making competence of cognitively impaired elderly persons', *The American Journal of Geriatric Psychiatry*, *10*(2), pp151-165.

Krefting, L. (1991) 'Rigor in qualitative research: The assessment of trustworthiness', *American Journal of Occupational Therapy*, *45*(3), pp214-222.

Krippendorff, K. (2004) 'Reliability in content analysis', *Human Communication Research*, *30*(3), pp411-433.

Kuper, A., Lingard, L. and Levinson, W. (2008) 'Critically appraising qualitative research', *British Medical Journal*, 337, pp687-692.

Lewis, J. and Ritchie, J. (2003) *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* SAGE publications.

Liamputtong, P (2009) 'Qualitative data analysis: conceptual and practical considerations', *Health Promotion Journal of Australia*, *20*(2), pp133-139.

Limpawattana, P., Tiamkao, S., Sawanyawisuth, K. and Thinkhamrop, B. (2012) 'Can Rowland Universal Dementia Assessment Scale (RUDAS) replace Mini-Mental State Examination (MMSE) for dementia screening in a Thai geriatric outpatient

setting?' *American Journal of Alzheimer's Disease and Other Dementias*, 27(4), pp254-259.

Lo, B. (1990) 'Assessing decision-making capacity', *The Journal of Law, Medicine & Ethics, 18*(3), pp193-201.

Macciocchi, S. N. and Stringer, A. Y. (2001) 'Assessing risk and harm: the convergence of ethical and empirical considerations', *Archives of Physical Medicine and Rehabilitation, 82(2),* pp15-19.

Miles, M. B. and Huberman, A. M. (1994) *Qualitative Data Analysis: An Expanded Sourcebook*. SAGE publications.

Milne, J. and Oberle, K. (2005) 'Enhancing rigor in qualitative description', *Journal of Wound Ostomy & Continence Nursing, 32*(6), pp413-420.

Moberg, P. J. and Rick, J. H. (2008) 'Decision-making capacity and competency in the elderly: a clinical and neuropsychological perspective', *NeuroRehabilitation, 23*(5), pp403-413.

Morse, J. M. (2000) 'Determining sample size', *Qualitative Health Research, 10*(1), pp3-5.

Moye, J., Butz, S. W., Marson, D. C. and Wood, E. (2007) 'A conceptual model and assessment template for capacity evaluation in adult guardianship', *The Gerontologist, 47*(5), pp591-603.

Moye, J., Gurrera, R. J., Karel, M. J., Edelstein, B. and O'Connell, C. (2006) 'Empirical advances in the assessment of the capacity to consent to medical treatment: Clinical implications and research needs', *Clinical Psychology Review, 26*(8), pp1054-1077.

Moye, J., Karel, M. J., Azar, A. R. and Gurrera, R. J. (2004) 'Capacity to consent to treatment: empirical comparison of three instruments in older adults with and without dementia', *The Gerontologist, 44*(2), pp166-175.

Moye, J. and Marson, D. C. (2007) 'Assessment of decision-making capacity in older adults: an emerging area of practice and research', *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 62*(1), pp2-11.

Mullaly, E., Kinsella, G., Berberovic, N., Cohen, Y., Dedda, K., Froud, B. and Neath, J. (2007) 'Assessment of decision-making capacity: Exploration of common practices among neuropsychologists', *Australian Psychologist*, *42*(3), pp178-186.

Neergaard, M. A., Olesen, F., Andersen, R. S. and Sondergaard, J. (2009) 'Qualitative description–the poor cousin of health research?', *Biomed Central Medical Research Methodology*, *9*(1), pp1-5.

Newberry, A. M. and Pachet, A. K. (2008) 'An innovative framework for psychosocial assessment in complex mental capacity evaluations', *Psychology, Health and Medicine, 13*(4), pp438-449.

Okai, D., Owen, G., McGuire, H. U. G. H., Singh, S., Churchill, R. and Hotopf, M. (2007) 'Mental capacity in psychiatric patients: A systematic review', *The British Journal of Psychiatry*, *191*(4), pp291-297.

Okonkwo, O. C., Griffith, H. R., Belue, K., Lanza, S., Zamrini, E. Y., Harrell, L. E. and Marson, D. C. (2008) 'Cognitive models of medical decision-making capacity in patients with mild cognitive impairment', *Journal of the International Neuropsychological Society*, *14*(02), pp297-308.

O' Regan, C., Cronin, H. and Kenny, R.A. (2011) Mental health and cognitive functioning, The Irish longitudinal study on ageing. Available at*:* http://*tilda.tcd.ie/assets/pdf/glossy/Chapter6.pdf* [Accessed 5 September 2015].

Pachet, A., Astner, K. and Brown, L. (2010) 'Clinical utility of the Mini-Mental Status Examination (MMSE) when assessing decision-making capacity', *Journal of Geriatric Psychiatry and Neurology*, *23*(1), pp3-8.

Parish, J., Carr, D., Suwinski, M. and Rees, C. (1990) 'Undressing the facts: The problems encountered by male occupational therapists', *The British Journal of Occupational Therapy, 53*(2), pp67-70.

Pope, C. and Mays, N. (2013) *Qualitative Research in Health Care* 3rd Ed. John Wiley & Sons.

Rabin, L. A., Borgos, M. J. and Saykin, A. J. (2008) ' A survey of neuropsychologists' practices and perspectives regarding the assessment of judgment ability', *Applied Neuropsychology, 15*(4), pp264-273.

Radomski, M.V. and Trombly Latham, C.A. (2008) *Occupational Therapy for Physical Dysfunction, 6th Edition.* Philidelphia: Wolters Kluwer/Lipincott Williams & Wilkins Health.

Reed, K. L. and Sanderson, S. N. (1999) *Concepts of Occupational Therapy*. Lippincott Williams & Wilkins.

Robertson, L. and Blaga, L. (2013) 'Occupational therapy assessments used in acute physical care settings', *Scandinavian Journal of Occupational Therapy, 20*(2), pp127-135.

Sachs, G.A. and Kirschner, K.L. (2000) 'Ethics in practice: Assessing decision making capacity', *Topics in Stroke Rehabilitation, 7(1),* pp62-64.

Sandelowski, M. (2000) 'Focus on research methods-whatever happened to qualitative description?', *Research in Nursing and Health, 23*(4), pp334-340.

Sandelowski, M. (2010) 'What's in a name? Qualitative description revisited', *Research in Nursing & Health, 33*(1), pp77-84.

Seale, C. (1999) 'Quality in qualitative research', *Qualitative Inquiry, 5*(4), pp465-478.

Sessums, L. L., Zembrzuska, H. and Jackson, J. L. (2011) 'Does this patient have medical decision-making capacity?', *Journal of the American Medical Association, 306*(4), pp420-427.

Sexton, M. (2012) 'Assessing capacity to make decisions about long-term care needs: Ethical perspectives and practical challenges in hospital social work', *Ethics and Social Welfare, 6*(4), pp411-417.

Seyfried, L., Ryan, K. A. and Kim, S. Y. (2013) 'Assessment of decision-making capacity: views and experiences of consultation psychiatrists', *Psychosomatics, 54*(2), pp115-123.

Shenton, A. K. (2004) 'Strategies for ensuring trustworthiness in qualitative research projects', *Education for Information, 22*(2), pp63-75.

Silberfeld, M. and Checkland, D. (1999) 'Faulty judgment, expert opinion, and decision-making capacity', *Theoretical Medicine and Bioethics*, 20(4), pp377-393.

Skinner, R., Joiner, C., Chesters, L., Bates, L. and Scrivener, L. (2011) 'Demystifying the process? A multidisciplinary approach to assessing capacity for adults with a learning disability' *British Journal of Learning Disabilities*, 39(2), pp92-97.

Stanley, M. and Nayar, S. (2014) 'Methodological rigour: Ensuring quality in occupational therapy qualitative research' *New Zealand Journal of Occupational Therapy,* 61(1), pp6-12.

Stewart, R., Bartlett, P. and Harwood, R. H. (2005) 'Mental capacity assessments and discharge decisions', *Age and Ageing*, 34(6), pp549-550.

Suleman, S. and Hopper, T. (2015) 'Decision-making capacity and aphasia: speech-language pathologists' perspectives', *Aphasiology*, 30(4), pp1-15.

Sullivan-Bolyai, S., Bova, C. and Singh, M. D. (2005) 'Experimental and quasi-experimental designs', *Nursing Research in Canada: Methods, Critical Appraisal and Utilization*, pp247-263.

Thomas, E. and Magilvy, J. K. (2011) 'Qualitative rigor or research validity in qualitative research', *Journal for Specialists in Paediatric Nursing, 16*(2), pp151-155.

Tong, A., Sainsbury, P. and Craig, J. (2007) 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups', *International Journal for Quality in Health Care, 19*(6), pp349-357.

Tunzi, M. (2001) 'Can the patient decide? Evaluating patient capacity in practice', *American Family Physician, 64*(2), pp299-306.

Venesy, B. A. (1994) 'A clinician's guide to decision making capacity and ethically sound medical decisions', *American Journal of Physical Medicine and Rehabilitation, 73*(3), pp219-226.

Volicer, L. and Ganzini, L. (2003) 'Health professionals' views on standards for decision making capacity regarding refusal of medical treatment in mild Alzheimer's disease', *Journal of the American Geriatrics Society, 51*(9), pp1270-1274.

Wales, K., Clemson, L., Lannin, N. A., Cameron, I. D., Salked, G., Gitlin, L. and Davies, C. (2012) 'Occupational therapy discharge planning for older adults: a protocol for a randomised trial and economic evaluation', *BMC Geriatrics,12*(1), pp1-7.

Willis, S. L. (1996) 'Everyday cognitive competence in elderly persons: Conceptual issues and empirical findings', *The Gerontologist, 36*(5), pp595-601.

Wong, J. G., Clare, I. C. H., Gunn, M. J. and Holland, A. J. (1999) 'Capacity to make health care decisions: Its importance in clinical practice', *Psychological Medicine, 29*(02), pp437-446.

Wong, J. G., Clare, I. C. H., Holland, A. J., Watson, P. C. and Gunn, M. (2000) 'The capacity of people with a mental disability to make a health care decision', *Psychological Medicine, 30*(02), pp295-306.

Woods, B. and Pratt, R. (2005) 'Awareness in dementia: Ethical and legal issues in relation to people with dementia', *Aging and Mental Health, 9*(5), pp423-429.

Yardley, L. (2000) 'Dilemmas in qualitative health research', *Psychology and Health, 15*(2), pp215-228.

Yilmaz, K. (2013) 'Comparison of quantitative and qualitative research traditions: epistemological, theoretical, and methodological differences', *European Journal of Education, 48*(2), pp311-325.

Appendix 1- Interview Schedule

School of Physiotherapy
Royal College of Surgeons in Ireland
123 St Stephen's Green, Dublin 2
INTERVIEW SCHEDULE

(Version 2 Date: 08/10/2015)
Title of Study: Occupational therapy practice in assessment of older person's capacity to return home-an exploratory study

Interviewer: Aine McNally, Occupational Therapist

Ensure the room is quiet and safe

Welcome participant

Introduce self and study

Discuss the format; dictaphone and time keeping

Turn on dictaphone and record start time

Begin the interview;

(A) <u>Client profile</u>

(1) Can you tell me about your occupational therapy experience to date?

Prompts: Years of experience, Previous practice contexts

(2) What is your current client profile and the services you provide?

Prompts: Age, Conditions, Practice area

(3) What is your understanding of decision making capacity?
Prompts: How is it assessed?

(4) Do you receive referrals for occupational therapy reviews in order for the medical team to determine an older person's capacity to return home?

Prompts: Frequency of referrals, What does the referral request, What is the prompt that triggered a DMC assessment?

(B) <u>Current practice</u>

(1) Can you explain the process when you receive a referral for an occupational therapy review, which the medical team have requested, in order to determine an older person's capacity to return home?

Prompts: Liaise with family/MDT, functional assessments (personal care/ domestic), cognitive assessments, instrumental activities of daily living assessments, home visits? On how many occasions do you see the person? Do you call at different times of the day? Do you liaise with family? Do you make recommendations to the medical team? What other factors do you consider?

(2) How did you develop that approach and what factors influence it?

Prompts: Is there a departmental protocol for occupational therapy practice? Is what you have described based on clinical experience? Is time a factor? Do you have the necessary assessment resources?

(3) What is the multidisciplinary practice?

Prompts: Is an occupational therapy referral standard practice? How do you report your information to the team? Is there a team meeting? How is this information relayed to the patient?

(4) As an occupational therapist what, if any, is the impact of your practice on this process?

Prompts: Do you complete assessment of functional abilities? Do you administer cognitive assessments? Where are the assessments completed? Would you consider a home visit? Do you act as an advocate for the patient?

(C) Assisted Decision Making Bill 2013

(1) I sent you a copy of part of the Assisted Decision Making Bill 2013 last week. Were you aware of this bill and what do you know about it?

Prompts: Functional approach to capacity determination, Are you aware that the individual does not necessarily have to recall the decision after it is made? Are you aware of the use of the terminology of will and preferences instead of best interests?

(2) Does / Will this Bill influence your practice?

Prompts: Does the multidisciplinary team discuss the Bill? Do you consider the Bill in your assessment process?

Appendix 2- Ethical Application Form

Appendix 3- Ethical Approval

Royal College of Surgeons in Ireland
The Research Ethics Committee
121 St. Stephens Green, Dublin 2, Ireland.
Tel: +353 1 4022205 Email: recadmin@rcsi.ie

RCSI
ROYAL COLLEGE OF SURGEONS IN IRELAND
COLÁISTE RÍOGA NA MÁINLEÁ IN ÉIRINN

Dr David Smith, Acting Chair
Dr Niamh Clarke, Convenor

15th October 2015

Ms Aine McNally
C/o Dr Frances Horgan,
RCSI School of Physiotherapy,
123 St. Stephens Green,
Dublin 2.

Ethics Reference No:	REC 1110
Project Title:	Occupational therapy practice in assessment of older person's capacity to return home-an exploratory study
Researchers Name (lead applicant):	Ms Aine McNally (MSc in Neurology and Gerontology, RCSI)
Principal investigator on the project (PI):	Dr Frances Horgan (RCSI School of Physiotherapy)
Other Individuals Involved:	Dr Deirdre Connolly (School of Occupational Therapy, TCD.)

Dear Ms McNally,
Thank you for your Research Ethics Committee (REC) application. We are pleased to advise that ethical approval has been granted by the committee for this study.

This letter provides approval for data collection for the time requested in your application and for an additional 6 months. This is to allow for any unexpected delays in proceeding with data collection. Therefore this research ethics approval will expire on **15th October 2016.**

Where data collection is necessary beyond this point, approval for an extension must be sought from the Research Ethics Committee.

This ethical approval is given on the understanding that:

- All personnel listed in the approved application have read, understand and are thoroughly familiar with all aspects of the study.
- Any significant change which occurs in connection with this study and/or which may alter its ethical consideration must be reported immediately to the REC, and an ethical amendment submitted where appropriate.
- Please submit a final report to the REC upon completion of your project.

We wish you all the best with your research.

Yours sincerely,

Niamh Clarke

PP Dr. Niamh Clarke (Convenor)
Dr David Smith (Acting Chair)

Appendix 4- Participant Information Leaflet

School of Physiotherapy
Royal College of Surgeons in Ireland
123 St Stephen's Green, Dublin 2
PARTICIPANT INFORMATION LEAFLET

(Version 2 Date: 08/10/2015)
Title of Study: Occupational therapy practice in assessment of older person's capacity to return home-an exploratory study

Principal investigator's name: Aine McNally
Title: Occupational Therapist, Our Lady of Lourdes Hospital, Drogheda
ainemmcnally@rcsi.ie
Supervisor name: Dr Frances Horgan
Title: Senior Lecturer Physiotherapy, RCSI, fhorgan@rcsi.ie
Co-investigator's name: Dr Deirdre Connolly,
Title: Senior Lecturer Occupational Therapy, Trinity College Dublin
connoldm@tcd.ie

You are being invited to take part in a research study carried out by Aine McNally. Before you decide whether or not you wish to take part, you should read the information provided below carefully. Take time to ask questions – do not feel rushed or under pressure to make a quick decision. You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'. Withdrawal is permitted at any time, without having to give a reason and without any personal consequence.

Why is this study being done?

The Assisted Decision Making Bill was released in 2013. When enacted, this will replace the current Lunacy Act of 1871. This legislation aims to support people who have difficulty in their decision making ability.

In the acute hospital, if there is doubt regarding a person's ability to make a decision, the medical consultant completes a capacity assessment. This capacity assessment can relate to many decisions but frequently for the older person it is regarding their ability to make a decision to live independently. Often, as part of this capacity assessment an occupational therapy review is requested. This study aims to explore the views and practice of hospital occupational therapists of their role in this capacity process.

Who is organising and funding this study?

This study is being conducted as part of a taught Master's program in Royal College of Surgeons in Ireland (RCSI). The above mentioned, Aine McNally, is conducting the study under the supervision of Dr Frances Horgan and Dr Deirdre Connolly. Any costs associated with conducting the study will be funded by the lead investigator, Aine McNally.

Why am I being asked to take part?

You are being asked to participate because of your experience as an acute hospital occupational therapist. The study wishes to establish your practice when you are asked to complete a review of an older person in order for the Consultant to determine their capacity to return home. The study also aims to gain an insight into your perspectives on your role in this process.

How will the study be carried out?

I (Aine McNally) wish to interview ten hospital occupational therapists in different hospitals. The interviews aim to explore your experience of this process and establish your current practice.
The interviews will be carried out from October to December 2015 at a location and time of your choice. The interviews will take 20-30 minutes to complete and will then be analysed to determine the experiences of occupational therapists.

What will happen to me if I agree to take part?

If you wish to take part you will contact the lead investigator, Aine McNally, by telephone or email. I will then send you a consent form to complete with a stamped addressed envelope in order to return it to me. We will arrange a location and a time of your chose for the interview to take place. The interview will last approximately 20-30 minutes and will be recorded using a dictaphone. The interview questions will be related to your current practice in the assessment of older person's capacity to return home. A copy of the Assisted Decision Making Bill 2013 will be forwarded to you one week prior to the interview. The interview will include one question on your views on the Assisted Decision Making Bill 2013.

What are the benefits?

There are no direct benefits associated with taking part. However, you will assist with increasing the knowledge of occupational therapy practice in the assessment of older person's capacity to return home.

What are the risks?

There are no risks associated with taking part in this study

Will it cost me anything to take part?

The costs incurred by you will be the transportation costs of getting to the location that you have selected for the interview to take place.

Is the study confidential?

- Once the interviews are completed the recordings will be transcribed into a word document within two days.
- The dictaphone recordings will then be deleted.
- The transcripts will be coded and referred to as 'participant 1, 2 etc
- There will be one document which will detail which code corresponds to which participant and where each interview took place. So for example P1 – Anne Ashley, Our Lady of Lourdes Hospital, Drogheda. This document will ensure that if your wish to withdraw from the study at any time I can delete your transcribed interview.
- This document will be encrypted and stored in a unique folder on the RCSI hard-drive.
- This secure folder will contain all of the interview transcripts and consent forms.
- Only the lead researcher and supervisors will have access to this information.
- No participant or hospital will be named in the transcription.
- The information will be kept for five years in accordance with the RCSI policy after which time it will be destroyed.

Results

- A copy of the transcribed interview will be sent to each participant within one week of the interview taking place to ensure it is accurate and true and any necessary modifications you highlight will take place.
- It will not be possible to identify you in the results as no participant or hospital names or any identifiable pieces of information will be used.
- If you wish to read the completed study the lead investigator can send you a copy once it has been submitted and corrected.
- An article format of the study may be submitted to appropriate journals for publication.

Future Research Studies
Once the study is completed one copy of the transcriptions will be kept in a folder on the RCSI secure server for five years.

Where can I get further information?

If you need any further information now or at any time in the future, please contact the lead investigator;

Lead Investigator
Name: Aine McNally,
Address Magheraboy Road,
Carrickmacross,
Co. Monaghan.
Phone No: 0879172070
Email: ainemmcnally@rcsi.ie

Supervisor: Dr Frances Horgan
Senior Lecturer Physiotherapy,
RCSI, fhorgan@rcsi.ie. 014022472

Co-supervisor: Dr Deirdre Connolly,
Senior Lecturer in Occupational Therapy,
Trinity College Dublin, connoldm@tcd.ie. 018963210

Appendix 5- Consent Form

School of Physiotherapy
Royal College of Surgeons in Ireland
123 St Stephen's Green, Dublin 2
PARTICIPANT CONSENT FORM
(Version 2 Date: 08/10/2015)

Title of Study: Occupational therapy practice in assessment of older person's capacity to return home - An exploratory study

Lead Researcher: Aine McNally
Occupational Therapist, Our Lady of Lourdes Hospital,
Drogheda, Co. Louth.
Phone number: 087 9712070
Email address: ainemmcnally@rcsi.ie

Supervisors: Dr. Frances Horgan, Senior Lecturer in Physiotherapy,
Royal College of Surgeons in Ireland.
Phone: 01 402 2472 Email: fhorgan@rcsi.ie

Dr. Deirdre Connolly, School of Occupational Therapy,
Trinity College Dublin.
Phone: 018963210 Email: connoldm@tcd.ie.

I have read and understood the **Information Leaflet** about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	***Yes*** ☐	***No*** ☐
I understand that I don't have to take part in this study and that I can opt out at any time. I understand that I don't have to give a reason for opting out	***Yes*** ☐	***No*** ☐
I understand that an audio recording will be made and that I have the right to review and edit any transcripts to which I have contributed.	***Yes*** ☐	***No*** ☐
I have been given a copy of the Information Leaflet and this completed consent form for my records.	***Yes*** ☐	***No*** ☐

Storage and future use of information: I give permission for data to be stored for possible future research: (a) related to the current study subject to research ethics committee approval (b) related to the current study only if consent is obtained at the time of the future research subject to research ethics committee approval.	***a*** ☐	***b*** ☐
I give permission for data to be stored for possible future research related to the current study without further consent being required subject to research ethics committee approval.	***yes*** ☐	***no*** ☐
I give permission for data to be stored for possible future research: (a) unrelated to the current study subject to research ethics committee approval (b) unrelated to the current study only if consent is obtained at the time of the future research subject to research ethics committee approval.	***a*** ☐	***b*** ☐
I give permission for data to be stored for possible future research unrelated to the current study without further consent being required subject to research ethics committee approval.	***yes*** ☐	***no*** ☐

Participant Name (Block Capitals): _____

Participant Signature: _____ ***Date:*** _____

To be completed by the Principal Investigator- *I the undersigned have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.*

Name & Qualifications (Block Capitals): _____

Signature: _____ ***Date:*** _____

Appendix 6- Curriculum Vitae

PERSONAL & CONTACT DETAILS

AINE McNALLY

Address: Magheraboy Road, Carrickmacross, Co. Monaghan **Age**: 10/02/1983

PROFESSIONAL BACKGROUND

EMPLOYMENT RECORD

May 2015- Present day **Our Lady of Lourdes Hospital, Drogheda, Co. Louth**

Senior Occupational Therapist, Stroke

2010- 2015 **St. James Hospital, Dublin.**

Occupational Therapist

I am proficient in;

- Assessment of complex seating and postural needs and provision of specialized seating and pressure relieving products.
- Education of nursing staff and families on patients' postural and positioning needs.
- Facilitation of groups such as falls prevention, upper limb rehabilitation, reminiscence and cognitive stimulation groups.
- Goal setting and rehabilitation programs for ADL' s and IADL's
- Administration of cognitive assessments, perceptual assessments, functional assessments, home evaluations, complex discharge panning and hoist training.
- Facilitation of occupational therapy students and supervision of staff grade occupational therapists.

EDUCATION & ACCREDITATIONS

Education

Royal College of Surgeons,	**Msc Gerontology & Neurology**
Commence 2014	
Trinity College Dublin, 2005-09	**B.Sc. (Occupational Therapy: 2.1)**
Trinity College Dublin, 2002-05	**Medicinal Chemistry**
Bruce College Dublin. 2002	**Leaving Certificate**

Appendix 7- Sample node from Nvivo analysis

<Internals\Interviews\Participant 1> - § 5 references coded [5.12% Coverage]

Reference 1 - 1.60% Coverage

My issue with standardised assessments is that I think that often the way in which the information is presented is important. I think that if it is presented clearly, in form t of them, perhaps in written format then they might be able to formulate a decision themselves.

Reference 2 - 0.32% Coverage

I would ascertain if they needed a cognitive assessment

Reference 3 - 1.78% Coverage

I have, eh in the past, gone to complete a cognitive assessment with a patient in the afternoon and I would be very aware of their level of fatigue and alertness. And also eh with visitors in the afternoon there are more distractions. So I would try to schedule cognitive assessments earlier in the day

Reference 4 - 0.29% Coverage

I usually do cognitive assessments in the morning

Reference 5 - 1.13% Coverage

Eh yes, I would always be strong on that. As long as I feel it is deemed. I am very reluctant to complete a cognitive assessment without being able to back it up with a functional assessment.

<Internals\Interviews\Participant 2> - § 4 references coded [10.34% Coverage]

Reference 1 - 1.96% Coverage

Usually I start with a basic screen, one that has not been completed by the medical team. So eh I tend to veer away from the MMSE as I feel it is over used. One screen that I tend to personally start with is the RUDAS. My reason for using this is that it incorporates a higher level executive subtest that some of the other cognitive screens don't have. So that starts off looking at that higher level decision making and judgement.

Reference 2 - 1.13% Coverage

Capacity eh comes down to problem solving and weighing up risk and for this reason I feel that the MMSE does not tap into these components. It is a higher level decision making that is required and so I feel the RUDAS includes some of these elements.

Reference 3 - 1.26% Coverage

I then would complete a more in depth cognitive, so depending on the age profile I might complete an ACE III assessment. However, time doesn't always allow and so if I had to choose a further cognitive assessment or a functional assessment I would choose

a functional assessment.

Reference 4 - 5.99% Coverage

Em, my focus is on the impact of cognitive deficits and I break down what came from the functional assessment. I will relay cognitive scores but I focus on how that impacts on function.
So eh I break it down firstly into domains, so I'm not talking about cognition in the broad sense I talk about domains; executive function, memory, attention, sensory registration. But then I try to eh pin point exactly the risks that were identified or came from my assessments and then try where possible try to look at the likely implications of these. So if it is an attention deficit then primarily then how that snowballs and impacts on other domains and impacts on safety and function and the home. So I don't speak about cognition in the broad sense, I break it into the domains of cognition and feedback the outcome of the functional assessment and the potential risks that the patient could be exposed to. Then of course it is not all negative, em you discuss the measures that could be put in place to minimise or mitigate against those risks so you are not going in with a very negative. So you identify a, b and c however if we implement x, y, and z it might reduce the risks. So yeah it is a problem solving approach but ultimately you have to outline the risks that the patient could be exposed to, from your assessments, yeah

<Internals\Interviews\Participant 3> - § 1 reference coded [4.28% Coverage]

Reference 1 - 4.28% Coverage

Then looking at eh doing a cognitive screen; I tend to use the MOCA or the ACE-II as they are more robust in what they look at and they tell you a lot more in terms of higher executing functioning and they are more cognitively demanding than the MMSE. I think it's important to look at executive functioning as it is the area of cognition that would determine someone ability to plan, problem solve and their judgement skills and ……..em…its….one of the areas that looks at self-monitoring so in some ways it's their insight and their ability to manage in a novel situation which could happen at home. If you are at eh home on your own things are not always routine or structured.

<Internals\Interviews\Participant 5> - § 2 references coded [2.62% Coverage]

Reference 1 - 0.39% Coverage

then I probably do a cognitive screen maybe a MOCA or em an ACE III

Reference 2 - 2.24% Coverage

also I eh feel that the medical team focus too highly on the cognitive score….the number….so I feel the functional tells me more. A cognitive score could mean they left school early or they were too distracted to really focus but the functional assessment shows me how they manage….it is eh much more informative. I mean….the medical team can do a cognitive screen or the nursing staff

<Internals\Interviews\Participant 6> - § 4 references coded [7.77% Coverage]

Reference 1 - 0.60% Coverage

do a cognitive screen so the main ones that we would here are the MOCA and the ACE

III

Reference 2 - 2.45% Coverage

Yeah, so the initial context that would be on the ward but you know that is not an ideal context to assess someone in and for patients with a cognitive impairment in the acute hospital setting there can be loads of issues there so sometimes for example for a cognitive assessment we might bring them to a quieter room so maybe one of the OT treatment rooms

Reference 3 - 1.90% Coverage

you need to give the patient that chance especially in the acute hospital cognitive ability can vary so much and depending on the times of the day too , delirium is another thing that can impact on it so you really need to take all of those things into account so let me see,

Reference 4 - 2.82% Coverage

for example last week the team came to OT looking for a cognitive assessment saying it is paramount for discharge planning but the patient has a delirium and it is not appropriate to complete a cognitive assessment at this point and that can be a big barrier in the acute hospital and people are so focussed on moving patients through the system and discharge planning and the patient just needs a bit of time

<Internals\Participant 4> - § 5 references coded [15.57% Coverage]

Reference 1 - 4.93% Coverage

would complete a cognitive and a functional assessment for that person so that this would highlight to us any concerns around their cognition or their safety awareness and we would do the Health and Safety Questionnaire which would highlight to us difficulties with eh making decisions around hypothetical safety scenario's so say if there was a fire in their house what would they do or if eh someone knocked on their door at night time and they were not expecting anyone what would they do, so at least we would get a bit of an understanding of that you know……but cognition is not capacity eh they are two separate things so eh we would always be referring to the medical consultant or the geriatrician to make that decision around capacity but our cognitive assessments might just highlight difficulties they are having with recall and attention which actually contribute to them not having capacity but these assessments don't tell us if someone has or doesn't have capacity

Reference 2 - 3.36% Coverage

Yeah, I actually got those from my mental health placement in college, they are form the Independent Living Skills which I think is mostly used in the mental health setting yeah, but I took it from there because I think it is relevant who patient would manage in hypothetical safety scenarios and what they could come up with, can they problem solve and come up with solutions and eh these are the types of things that eh could happen at home. So it looks at what would you do if you smelled gas at home, em what would you do if there as a fire and eh what if you were losing weight eh its just to see what they would do or how they would get help in those situations

Reference 3 - 1.46% Coverage

I wouldn't normally use that Health and Safety Questionnaire unless |I was querying their capacity as I fell that it eh brings it back to function which is what I want to look at as an occupational therapist, to be able to say that I would have concerns about them with regard to x, y, z

Reference 4 - 3.93% Coverage

when I first came here there was very few occupational therapists and the wards weren't used to us and there was this one cognitive assessment called the CAPE: Clifton Assessment Procedures for the Elderly and the department had been using it and most of the medical team and staff thought that this cognitive assessment was the capacity assessment. I think eh it was because they sound alike and also this assessment makes recommendations of discharge destination so home or a residential care facility. And people always think that cognition and capacity are the same thing and it isn't. But we don't have any policy on it but when we kept getting asked by the wards to do a capacity assessment and they would ask for the CAPE so we just stopped using it, it was awful really.

Reference 5 - 1.88% Coverage

now when we use different assessment, the MOCSA, ACE III, RUDAS the medical teams have to come to us and ask us what it means so we get the opportunity to explain it and say where the deficits are and eh what that all means for the patient. Yes we will give a score but because we use a different assessment they can't just assume the decision making ability of the patient.

<Internals\Participant 7> - § 2 references coded [8.50% Coverage]

Reference 1 - 3.23% Coverage

for me it would be looking at a MOCA assessment or an ACE III, something a bit more comprehensive em but I suppose for me doing a cognitive assessment I would always back it up with a functional assessment and the decision making is also along their safety awareness and their executive functioning and their cognitive flexibility and within the team so whether that is in the clinical notes or in a family meeting or at an MDT it is me giving a description of how that patient is managing in everyday tasks and that would be my role I fell to feedback…

Reference 2 - 5.26% Coverage

So then doing a quick cognitive screen with them so I would usually ask some orientation questions such as time, person, place, and reason for admission, how do they feel they are managing at the moment and do they feel that they need more assistance or more family supports you know to really work out what are their thoughts because a lot of the time people are veering towards that and they are making that decision for themselves. From there it would be doing the cognitive assessment; maybe the MOCA, I do try and stay away from the MMSE because we are not licenced to use it in our hospital and the ACE III is something we use at the moment but I have also been introduced to the mini ACE which is a new assessment and I think it is really important that we look at new assessments as well which might actually suit a lot of our clients a lot better so it is about looking at the evidence base.

<Internals\Participant 8> - § 2 references coded [10.51% Coverage]

Reference 1 - 1.39% Coverage

And em the safety part of the Cam is really useful and it asks what you might do if you had a fall and the answers from that will tell you a lot of information as a therapist.

Reference 2 - 9.12% Coverage

If the case is very clear cut and I have been involved in those cases where the patient has such a significant cognitive impairment well then I am not going to do a cognitive assessment just in order to have one completed as that is very distressing for that patient and it does not inform anything or tell me something that we all don't already know. It might agitate them just in order to fill out a CSARS form so I will say it is inappropriate…….But in the other cases it is choosing an appropriate cognitive assessment so if it is the MMSE then it is knowing that it's standardised for the over 65years only and to document that ……..so yeah choosing the most appropriate cognitive assessment so some of the assessment are very long so that would be a factor in choosing a cognitive assessment so there is now a mini ACE available and the literature appears to support its validity and em it is a brief screening tool. And the patient's educational background is another factor so if they left school very early then you may have to choose a different assessment. ……or if it is a younger person then it may be the CAM so it does depend on the patient……

<Internals\Participant 9> - § 2 references coded [8.22% Coverage]

Reference 1 - 2.61% Coverage

You complete a cognitive screen and then in the functional assessment you are looking to see if those cognitive deficits are translating into function. Em I think sometimes if the issue of capacity has been raised within the MDT sometimes further cognitive evaluations may be completed particularly if it is relating to capacity and you know that it is an issue that or that it is something that is going to come up, then I may complete further assessment to do with executive functioning.

Reference 2 - 5.62% Coverage

Em from a screening point of view I usually use an ACE II but if someone has a poor educational background I would choose a RUDAS as it was created for those with a reduced educational level. Then depending on the cognitive deficits that were highlighted in the cognitive screen I would complete a Rivermead Behavioural Memory or a BADS especially if the deficit was around the area of executive dysfunction. Em I would particularly take subsections of the BADS around safety and problem solving ability. I do that because its important look at executive function and meta-cognition and safety and problem solving abilities with novel tasks particularly for the person going home and if a light bulb goes will they know what to do or if an alarm goes off will they know what to do. It is looking at those higher level skills; problem solving especially around fire alarms, and use of pendant alarms and why and when they would use that. And then there are subsections of the CAM that can be useful in relation to use of a toaster and what would you do scenarios….